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ABSTRACT

This guide to pervasive developmental disorder (PDD) or autistic spectrum disorder (ASD) first provides a review of the literature on defining characteristics of PDD/ASD, causes of PDD, and diagnosis of PDD. Review of intervention and treatment comprises the major portion of the paper. After briefly considering parent education, this section examines behavioral interventions including positive behavioral support, applied behavior analysis, and pivotal response training. Therapeutic and educational interventions are discussed next and include floor time play therapy, occupational therapy, sensory integration therapy, speech therapy, social skills training, the Treatment and Education of Autistic and Related Handicapped Children program, and transitional planning. A discussion of major psychotropic interventions completes the section on intervention. The following section considers how PDD affects families. A final discussion notes that the literature review yielded inconclusive results regarding causality, although there is agreement that ineffective parenting does not cause PDD; that no diagnosis should be based on only one test; that there is agreement that early diagnosis and intervention produce more favorable outcomes; and that parents need to advocate for their children. Appendices include a sample of the Childhood Autism Scale and the Diagnostic Checklist for Behavior Disturbed Children, a sample Individualized Education Program, a list of resources, and case studies. (Contains 26 references.) (DB)

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Pervasive Developmental Disorder

Client-Centered Approach

A Guide for Parents and Teachers

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Pervasive Developmental Disorder

Introduction

The number of cases of Pervasive Developmental Disorder (PDD), also referred to as Autistic Spectrum Disorder (ASD), is increasing. According to researchers (Turnbull R., Turnbull, A., Shank, M., Smith, S., & Leal, D., 2002), this increase may result from better methods of identification, newness of the field of special education, and federal mandates of the Individuals with Disabilities Education Act (IDEA). Estimates are that one out of every 1,000 children has a PDD. Of these, one third will be diagnosed with autism. Others (Myles & Simpson, 1998; Waltz, 2002) contend the prevalence of PDD is as high as one in 500. Males are two times more likely to be diagnosed with PDD than females.

Researchers (Kabot, Masi, & Segal, 2003; Kelly, 2000; Myles & Simpson, 1998; Waltz, 2002) believe that ASDs originate from a combination of genetic, neurological and environmental factors. ASD affects communication and social skills, as well as, emotional expression and mental capabilities. The effects of ASD on a child are far-reaching. PDD affects a child's interaction with the environment, school performance, self-esteem, family life, and ultimately, the child's future.

In the 1940's Leo Kanner and Hans Asperger independently used the term autistic to describe children who had unusual reactions to sensory stimuli, exhibited stereotyped and repetitive behavior, and preferred solitary pursuits (Olney, 2000; Waltz, 2002). They believed autism to be an inborn biological disorder. Contrastingly, Bruno Bettleheim believed autism was psychological and resulted from parent-child pathology (Olney, 2000;

Waltz, 2002.). The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994) stated that although the term "childhood schizophrenia" was once used to refer to ASDs, there is considerable evidence that schizophrenia is a separate disorder. According to Kabot, Masi, and Segal (2003), PDDs are more common in childhood than cancer, Down syndrome, or cystic fibrosis.

Defining Characteristics of PDD/ASD

Waltz (2002) contended that "PDD is a label of convenience created by psychiatrists, and that a diagnosis is reached through the process of elimination" (p. 1). Some symptoms of PDD are visible (e.g., hand waving/wringing, social ineptness), yet they are difficult to medically define and treat. Although PDD is classified as a psychiatric disorder, it does not respond to medication and talk therapies used to treat other psychiatric problems (Waltz, 2002). Further, PDD is not the same as mental retardation or emotional disturbance even though mental retardation and behavior problems may coexist with PDD. Autistic disorder is the best-known ASD, but less severe forms of the disorder are at least twice as common and much more vaguely defined.

According to the DSM-IV (APA, 1994), pervasive developmental disorders include autisticdisorder, Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder, Not Otherwise Specified (PDD NOS). PDD NOS also includes atypical autism. Rett's disorder and childhood disintegrative disorder are more clearly defined and less confusing to identify than the remaining PDDs (APA, 1994).

According to the DSM-IV (APA, 1994), PDDs share common characteristics. They are characterized by severe and pervasive impairment in reciprocal social skills, communication skills, and in the presence of stereotyped, restricted, and repetitive interests and activities. There may be abnormalities in cognitive skills and co-occurring medical conditions, such as central nervous system abnormalities. Children with PDD may also exhibit behavioral symptoms, such as impulsivity, aggressiveness, hyperactivity, and attention problems. Further, individuals diagnosed with PDD often experience sensory problems, (e.g., high tolerance for pain, over/under sensitivity to touch, sounds or odors, and be "picky eaters"). They may also exhibit sleep problems.

According to the DSM IV criterion, PDDs are usually evident in the first five years of life. Autistic disorder typically manifests in children before age three, whereas, Asperger's has a later onset (e.g., when the child is five or six years of age). On the other hand, childhood disintegrative disorder and Rett's disorder occur after a period of normal development (APA, 1994). Symptoms of ASDs in infants and very young children are sometimes overlooked or mislabeled. Lack of eye contact, delayed speech, failure to respond to parents, and odd sounds and movements may indicate the presence of an ASD. Favorable outcomes are more likely when a child receives early intervention and treatment.

Myles and Simpson (1998) reported that PDD "has been identified throughout the world among all racial, ethnic, economic and social groups" (p. 7), and the prevalence of PDD has increased worldwide. Waltz (2002) argued that the term pervasive developmental disorder is misleading because the individual is usually not delayed in every area and because

development varies from child to child. Waltz also argued that PDD should be classified as a medical condition instead of a psychiatric condition since it is a neurological disorder, like epilepsy and Alzheimer's disease.

PDD often becomes more evident when a child enters school, as teachers observe the child's lack of social interaction and reciprocity, inattentiveness, and difficulty staying on task. Delays in fine and gross motor skills, which are common in PDD, may manifest more readily when the child is learning to cut, write, and tie his shoes.

Causes of PDD

Acording to Turnbull et al., (2002) "autism is caused by brain or biochemical dysfunction before, during, or after birth (p. 346). Further, they cited the Autism Society of America, which reported, "no known factors in the psychological environment of a child have been known to cause autism," (p. 347).

In the early 1940s, Bruno Bettelheim and other doctors believed that emotionally unavailable and abusive parents, especially the mother, caused children to develop PDD (Olney, 2000; Waltz, 2002). Bettleheim used the term "refrigerator mom" to describe the emotional aloofness of mothers who had children with autism. Parents were encouraged to place these children into institutions because "irreparable damage had already been done in infancy" (Waltz, 2002, p. 4). Even though researchers have not identified the exact causes of PDD, they concur that "bad" parenting is not one of them. So what does cause PDD?

Currently, research is being conducted in several areas to examine the etiology of PDD. DSM-IV (APA, 1994) noted that PDD is sometimes seen with medical conditions, such as chromosomal or central nervous system abnormalities or congenital infections, and that there was an increased risk of ASD among siblings of individuals with the disorder. Twin studies provide strong evidence for genetic components. A recent study by Koczat, Rogers, Pennington, and Ross, (2002) estimated that over 90 percent of etiologic factors of PDD are genetic. Others (Kelly, 2002; Myles & Simpson, 1998; Waltz, 2002) agreed that genetic factors play a role in PDD, although the exact nature of that role is still under investigation. Tsai (1999) and Buitelarr and Willemsen-Swinkels (2000) reported that ASD is a neurobiological disorder.

Geneticists speculate that more than 15 genes may be involved in ASD/PDD. Several researchers (Kabot et al., 2003; Kelly, 2002) reported that two genes, reelin and HOXA1, have been associated with autism. They argued that mutations on chromosome 15, fragile X syndrome, and tuberous sclerosis need to be examined. They reported that half of the children diagnosed with tuberous sclerosis have autistic features. Further, Buitelaar and Willemsen-Swinkles (2002) reported using an affected sibling pair strategy resulted in a promising linkage to chromosome seven. Recently, research using computerized brain scans revealed that the parietal, temporal, and occipital lobes are more voluminous in those affected with autism (Sparks et al., 2002; Waltz, 2002).

Another area of research into the causes of PDD lies in studying neurotransmitters in the brain. Neurotransmitters are chemicals that transmit electrical signals in the brain. The neurotransmitters thought to be involved in autism are serotonin, norepinephrine, and dopamine.

Serotonin controls sleep, mood, and some types of sensory perception. Waltz (2002) reported on a study, which revealed that people with autism tend to have elevated amounts of serotonin in their blood. Dopamine helps control motor skills, thought patterns, and regulates how hormones are released. Medications that block dopamine have been useful to some people with ASD, possibly because of differences in how people with ASD use dopamine. Norepinephrine is used by the central nervous system and the sympathetic nervous system. It controls arousal, the fight or flight response, anxiety, and memory. There seems to be a difference in how people with ASD process norepinephrine. Medications, such as SSRIs, affect how neurotransmitters work and have produced changes in autistic symptoms (Waltz, 2002).

Other factors linked to ASD and under investigation include metabolic or immune system differences, gastrointestinal problems, infections, and exposure to toxins (Waltz, 2002). Gastrointestinal problems and allergies are more common in individuals with ASD. Waltz (2002) cited one research project, the Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS), which found that when some children are exposed to streptococcus

bacteria, they develop antibodies that mistakenly attack the basal ganglia in the brain as well as the strep bacteria. The symptoms of these children are consistent with obsessive-compulsive disorder (OCD), which is often a secondary diagnosis in people with ASD (Waltz, 2002). It is not surprising, then, that many parents of children with ASD reported that their children had early and frequent ear infections. This writer examined approximately 1,000 files of children seen at a mental health clinic. Of those children, 65-75% had frequent ear infections as reported by their parent/guardian.

One metabolic disorder associated with autistic features is phenylketonuria (PKU). PKU results when the body has difficulty processing the protein, phenylalanine. The protein builds up in the bloodstream and eventually causes brain damage (Waltz, 2002). Today screening for PKU and mandates for labeling help decrease this metabolic malady.

Environmental toxins, such as mercury and PCBs, and childhood immunizations have been implicated in developmental delays. British researcher, Dr. Andrew Wake (as quoted by Waltz, 2002) published studies on the potential links among measles, gastrointestinal problems, and autism. Further, some vaccines contain the preservative thimerosol, a derivative of mercury, which may cause neurological problems. Most children tolerate vaccines, but children who inherit genes associated with autism may not do as well.

Diagnosing PDD

Early intervention is important for the treatment and favorable long-term prognosis of PDD. The Individuals with Disabilities Education Act (IDEA) mandates that each local education association (LEA) seek out and identify children with disabilities. Early intervention programs serve children ages 0-3. Once children are in school, they are screened, and if applicable, referred for a complete nondiscriminatory evaluation. If evaluation results indicate that the child has one or more of the15 categories of disability listed under IDEA, the child is eligible to receive special education and related services.

According to Waltz (2002), screening for PDD can begin in several ways. A child may be referred for screening by a parent, childcare worker, school official, or pediatrician. Often the first person to become aware of parents' concern regarding their child is the pediatrician. Unfortunately, pediatricians and general practitioners do not always recognize the early signs of PDD and may, consequently, reassure parents that children develop at their own pace. Therefore, parents play a vital role in getting a proper diagnosis and services for their child.

When a child is suspected of having PDD, assessment should begin as quickly as possible. Ideally, a multidisciplinary team should do screening with an expert in autistic spectrum disorders as part of the team. Parents should provide a thorough developmental and family history so that the treatment team has a complete biopsychosocial evaluation. Assessment should include a medical,

vision, and hearing test. An audiological evaluation is crucial because children with central auditory processing problems often exhibit communication, attention, and social problems like those found in PDD. Diagnoses should never be based on the results of a single test.

The Checklist for Autism in Infants and Toddlers (CHAT) is the most widely known screening instrument for young children (Waltz, 2002). If the results suggest autism, further assessment is recommended. Another instrument used for early detection and intervention is the Screening Tool for Autism in Two-Year Olds (STAT). STAT is currently being revised and is an empirically derived measure. The STAT differs from the CHAT in that it was developed as a second-stage screening device to differentiate children with autism from children with other developmental disorders (Kabot et al., 2003). The Parent Interviews for Autism (PIA) consists of a set of questions for parents and is often used when diagnosing younger or nonverbal children.

The Autism Diagnostic Observation Schedule (ADOS) is used to conduct an evaluation via direct observation of the child. "Many evaluators consider the ADOS to be the "gold standard" in autism-testing instruments" (Waltz, 2002, p. 53). The ADOS is more accurate and less subjective than some other instruments. The Childhood Autism Rating Scale (CARS) is another direct observation instrument used by psychologists. The Developmental Behavior Checklist (DBC)

is a useful tool for assessing emotional and behavioral problems in children with developmental disabilities (Dekker et al., 2002).

Goldstein (2002) reviewed the use of the Asperger's Syndrome Diagnostic Scale (ASDS) in diagnosing PDD. He found that the ASDS could not distinguish among the different types of PDDs. Contrastingly, Leekman, Libby, Wing, & Taylor (2002) found that the Diagnostic Interview for Social and Communication Disorders (DISCO) was a reliable instrument for diagnosing ASD.

The Wechsler Intelligence Scale for Children-III (WISC-III) and the Wechsler Individualized Achievement Test (WIAT) are administered to children in school. When a significant discrepancy is noted between a child's intelligence and actual achievement, a learning disability is suspected. The child is then referred to the Child Study Team for a nondiscriminatory evaluation. If the child is found to have a disability, such as PDD, then special education and related services are implemented according to the child's individualized educational program (IEP). If a parent disagrees with a diagnosis or evaluation results, obtaining a second opinion is recommended. A parent's right to an independent educational evaluation is also outlined in IDEA's policies and procedures.

Intervention & Treatment for PDD

Currently, no cure exists for pervasive developmental disorders Subsequently, treatment modalities for PDD are as varied as the disorder. The guiding

principles underlying any treatment option should be interventions that are comprehensive, collaborative, and individualized.

Margaret Mead described individualization succinctly (as quoted by Levine, 2002):

> If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each diverse human gift will find a fitting place. (p. 307).

Parent Education

Once an accurate diagnosis has been obtained, parents/guardians need to educate themselves about PDD/ASD. Education enables parents to find the most effective treatment for their child and helps the parent feel empowered. Knowledge is crucial when collaborating with educators, psychologists, and physicians. It is important to educate others, as well, because PDD has many social implications. Information can be garnered from books, web sites, lectures, and from other parents who have children with PDD. Attending a support group can be beneficial.

Parents are often unsure of how much information to give a child who asks, why am I different? Doctors E. M. Hallowell and J. R. Ratey (1994) worked with children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). They recommended the following, which may also be helpful for PDD:

1. Tell the truth
2. Use words a child will understand
3. Answer questions and ask for questions
4. Tell the child what PDD is and is not
5. Give examples of positive role models, someone the child is familiar with
6. Caution the child to not use the disability as an excuse
7. Coach the child on how he might answer questions others ask him
8. Offer plenty of reassurance and praise (p. 217-220).

Additionally, parents should use age-appropriate, simple language so the child is not confused. Give the child an opportunity to process the information, express any feelings, and normalize the experience as much as possible.

Behavioral Interventions

Many researchers (Kabot et al., 2003; Turnbull et al., 2002; Waltz, 2002) agree that behavioral intervention programs are effective in the management of ASD. Behavior modification, based on the work of B. F. Skinner, originally worked on a system of reward and punishment. Today, behavioral programs include positive behavioral support, applied behavioral analysis (ABA), and pivotal response training (PRT) among others.

Positive behavioral support (PBS) is a proactive, problem-solving, and databased approach that has shown successful outcomes for students (Turnbull et al., 2002). Positive behavioral support is a comprehensive approach that focuses on changing the environment to prevent the impeding behavior from happening in the first place.

Conducting a functional assessment is the foundation for PBS implementation. A PBS program encompasses clearly defined behavioral expectations, positive feedback, and universal support (Turnbull et al., 2002). The child is taught what behavior is expected and is given the opportunity to practice targeted behaviors. This may be broken down into small discrete steps and incorporated into lesson plans. The child is given positive affirmations, tickets for a treat or some other reward for success.

Applied behavior analysis (ABA) developed by Lovaas, is based on behavior modification (Waltz, 2002). ABA is sometimes referred to as discrete trial training because it is structured around short drills that help children learn skills that build the ability to respond naturally. ABA originally required 30-40 hours per week of one-on-one intervention. However, Lovaas's original study involved children with moderate to sever autism. For children with PDD/ASD who already have some skills, combining fewer hours of ABA with other interventions may be sufficient. Family participation is important in ABA programs.

As stated by Waltz (2002), Lovaas's ABA program consists of:

1. Observe the behavior you want to change. Take a baseline measurement, chart behavior, and its antecedents.
2. Make a hypothesis about what the behavior is trying to communicate and design an intervention based on hypothesis.
3. Have a positive goal broken down into small steps.
4. If you want to initiate a behavior, make a goal and break it down into small components.
5. Apply the intervention using positive reinforcement for each instance of desired behavior.
6. Assess the effectiveness of the intervention and adjust as needed. (p. 148-149)

Although the Lovaas program is expensive ($20,000-30,000), the steps involved are generic enough that special educators and parents should be able to incorporate the principles without having to purchase the program. Some parents are demanding that their school system pay for the Lovaas program, and in many instances, parents are winning (Waltz, 2002).

Pivotal response training (PRT) is a behavioral intervention developed by. Koegel and Schreibman that involves trials in pivotal behaviors such as motivation and responsivity to multiple cues (Koegel & Schreibman, 2003; Waltz, 2002). Pivotal behaviors are those that are central to a wide area of functioning, thus increasing generalization. Trials take place in a child's natural environment, such as at school or while playing. PRT works to improve motivation through components, such as giving a child choices and practicing turn taking. Moreover, language, social, and play skills are improved. Another component of PRT is that instruction be clear, uninterrupted, and appropriate to the task and interspersed with maintenance tasks. PRT includes giving a child choice and including multiple components when appropriate (Koegel & Schreibman, 2003). Reinforcers should be contingent upon behavior, administered following any reasonable attempt to respond, and related to the desired behavior in a direct way.

PRT differs from ABA in that PRT is more naturalistic and child-centered, whereas, ABA is a more structured, therapist-directed approach. Another advantage to PRT is that it can easily be transferred to computer play. Many children with PDD love computers because they are predictable, visible, and provide sensory stimulation (Thorp, 2003). Computer play can target motivation and increase the child's interest in learning.

Thorp (2003) noted several steps in creating effective computer play. First, you must have the child's attention. Holding the computer mouse in front of your face can do this; when the child seeks the mouse, make eye contact and address the child. Second, use clear prompting to elicit a response from the child, e.g., do you click on the red dot or the black square. Computer PRT is an excellent tool for teaching a child about taking turns. Let the child choose what game to play and then take turns. Turn taking also provides an opportunity to practice language skills, such as pronouns. For example, ask the child whose turn is it? The child will say my turn or your turn. This also incorporates the child choice component of PRT. Finally, be sure to reinforce the child's efforts (Thorp, 2003).

Therapeutic and Educational Interventions

Floor time play therapy uses developmental principles to help children build social, emotional, and communication skills. Stanley Greenspan of George Washington University and the Washington Psychoanalytic Institute is a proponent of floor time play therapy. Floor play is an individualized relationship based intervention (Waltz, 2002).

This intervention is less like behavior drills and more like play. Greenspan suggests that floor time therapy be the basis of early intervention and school programs for children with ASDs. Greenspan reported that 58% of the children with PDD-NOS and autism who participated in his program for two or more years, showed significant improvement as measured by the CARS (Waltz, 2002).

Floor time play therapy is easier for a larger number of parents to use than some other methods.

Occupational and sensory integration therapies are based on the idea that individuals with sensory and motor problems have difficulty processing information received through their senses. *Occupational therapy* builds fine and gross motor skills through special exercises and is helpful for children (and adults) with ASD. OT can be fun and is easily incorporated into a variety of settings. In school settings, the purpose of OT is to help the child with skills, such as how to hold a pencil, improve balance, and manipulate buttons, zippers, and tying shoes.

Sensory integration therapy (SIT) was developed by Jean Ayres, an occupational therapist (Waltz, 2002). Many children with ASDs experience motor and sensory problems. For many people with PDD, sensory dysfunction is the norm. The tactile, proprioceptive, and vestibular senses are our most basic way of relating to the environment (http://bbbautism.com/sensory_ integration.htm). Some children with ASD will wear only soft clothes or be "picky" eaters. Sometimes the "picky" eating is due to the texture of food more than taste. Some children with ASD exhibit stereotypic movements. These behaviors, thought to be autistic, may actually be attempts to deal with sensory integration dysfunction (http://bbbautism.com/ sensory_integration.htm).

SIT is intended to reduce sensory disturbances related to touch, movement, and gravity. SI does not require expensive equipment and is easily incorporated into both a home and school setting. SI interventions are often included in occupational therapy sessions in school settings.

Research (Waltz, 2002; hhtp://bbbautism.com/sensory_integration.htm) suggested the following: for tactile sensory problems, brushing/joint compression technique, deep pressure massage or hugs, rolling the child up in a blanket are useful. For proprioceptive problems swinging, jumping, and joint compression exercises are helpful. Vestibular problems respond well to walking on a balance beam, balancing on a therapy ball, occupational therapy to strengthen fine and gross motor skills, and stair climbing. Researchers (Kabot et al., 2003; Waltz, 2002) recommended incorporating sensory experiences into the daily routines of children with PDD.

Speech therapy is one of the most widely used related services incorporated into early intervention and individualized educational plans. Speech and language problems such as, difficulty with expressive and receptive oral and/or written communication, disordered speech, and pragmatic deficits are common in individuals with PDD. Perseveration (e.g.,) is also common. Researchers (Waltz, 2002; Turnbull et al., 2002) suggested using a total communication approach, incorporating visual and auditory modalities. When a

child is exhibiting behavior problems, communication difficulties are often the root cause.

Social skills training is crucial for children with PDD since "impairment in reciprocal social interaction skills" (APA, 1994, p. 66) is a major component of the disorder. Individuals with PDD have difficulty understanding social cues, back and forth conversation, and body language. Younger children may show little interest in peer interaction and prefer solitary or parallel play. Older individuals may desire friendships but lack knowledge of the conventions of social interactions (APA, 1994). Individuals with PDD may have a limited concept of the needs of others.

Carol Gray, an educator, developed the technique of using social stories to teach social skills (Waltz, 2002). Social stories describe social situations in terms of social cues and appropriate responses and are helpful for individuals with PDD (Myles & Simpson, 1998; Turnbull et al., 2002; Waltz, 2002). Social stories increase appropriate behaviors, such as eye contact and respect for other's boundaries. They decrease inappropriate behaviors, such as aggression and inappropriate touching (Turnbull et al., 2002). Social stories can be utilized to teach cause/effect and flexibility. Music can easily be incorporated into social stories.

Myles and Simpson (1998) recommended using scripts with children who have Asperger's syndrome. Scripts can be incorporated into classroom and home

settings. Further, "when paired with peer interaction training, it provides a structured interactive routine that facilitates predictable responses" (Myles & Simpson, 1998, p. 79).

Treatment and Education of Autistic and Related Handicapped Children (TEACCH) was developed by Eric Schopler in the 1970s and is widely used in schools to educate individuals who have ASD (Turnbull et al., 2002; Waltz, 2002). "TEACCH is a highly structured program that integrates individualized classroom methods, services delivered by outside community organizations, and support services for families" (Waltz, 2002, p. 265).

Ferrante (2002) compared students who received TEACCH with students who were integrated in regular schools with a support teacher. Ferrante found the experimental group (students receiving TEACCH) scored higher than the control group when administered the Psycho-Educational Profile and the Vineland Adaptive Behavior Scale.

Transitional Planning for individuals with disabilities is mandated by IDEA and is required in a student's IEP. Transitional planning consists of classes, activities, and planning that prepare the student for independent living. Because transition is a lifelong process, transition planning should begin early and be ongoing. "Even in elementary school, teachers should begin discovering and encouraging student strengths" (as quoted by Turnbull et al., 2002, p. 134).

Myles and Simpson (1998) recommended the McGill Planning System (MAPS) because it is a person-centered team approach that emphasizes the whole person.

Olney (2002) recommended that rehabilitation specialists work with the person's individuality and unique abilities. She suggested that change be introduced gradually and thoughtfully, and that some behaviors be accommodated rather than extinguished. Olney also suggested that communication be clear and direct. She suggested interacting with a person with ASD through e-mail can be helpful. Minimizing eye contact, using a calm voice, and giving honest feedback are effective. Additionally, Hallowell and Ratey (1994) reported feedback as beneficial. They also recommend lists, schedules, and breaking large tasks down into smaller tasks to help individuals who have attention deficits.

According to researchers (Olney, 2002; Turnbull et al., 2002), transitional planning should be collaborative, individualized, and comprehensive. It should involve the student, parents, teachers, and professionals from community agencies. Special education students may require extra support during the transition from high school to adulthood. They should receive vocational rehabilitative services and/or college preparatory services. Students with disabilities are eligible for publicly funded education and/or services until age 22.

Psychotropic Interventions

Recent research (Buitelaar & Willemsen-Swinkels, 2002; Kelly, 2002; Tsia, 1999) showed certain psychotropic medications may help some

symptoms of PDD, such as inattention, depression, anxiety, aggression, and hyperactivity. Contrastingly, Waltz (2002) cautioned against the use of medication until other treatment modalities have been tried. Further, Waltz (2002) reported that most of the drugs used for ASDs are those that affect neurotransmitters, such as antidepressants, antiseizure drugs, neuroleptics, and stimulants.

Selective serotonin reuptake inhibitors (SSRIs) block certain receptors from absorbing serotonin, which improves neurotransmitter balance in the brain. The most widely known SSRI is fluoxetine or Prozac. Other SSRIs include Luvox, Paxil, Zoloft, and Celexa. Prozac and Zoloft typically have an energizing and focusing effect, whereas, Paxil has a calming effect (Waltz, 2002). In one study (Kauffmann, Vance, Pumariega, & Miller, 2001), fluvoxamine was shown to be effective in reducing stereotypical, repetitive behaviors, anxiety, and aggression in individuals with PDD.

Before the existence of SSRI drugs, tricyclic antidepressants were used. Tricyclic antidepressants include amitriptyline (Elavil), clomipramine (Anafranil), nortriptyline (Pamelor), and others. Clomipramine is the tricyclic antidepressant most often prescribed for ASD (Waltz, 2002). Clomiprramine is used for obsessive-compulsive behavior, depression, and panic disorder.

Most antianxiety drugs are in the benzodiazepine family and can be addictive (e.g., Xanax, Valium). They slow down central nervous system activity. Non-

addictive drugs such as Buspirone may be a better choice. Waltz (2002) cited one study that showed BuSpar was useful for reducing aggressive behavior, hyperactivity, and stereotypic movements in some people with ASD.

Some individuals with ASD experience seizures and in some cases, seizures may be the root cause of an ASD, according to Waltz (2002). Antiseizure medications include carbamazepine (Tegretol), clonazepam (Klonopin), gabapentin (Neurontin), valproic acid (Depakote), and topiramate (Topamax). Depakote and Tegretol are the antiseizure medications used most often to treat symptoms of PDD. Waltz (2002) cited one study that found Depakote use in individuals with autism had substantial benefits.

According to Waltz (2002), stimulants are the drugs most frequently prescribed to children with ASDs, especially if hyperactivity and attention problems are present. On the other hand, Martin, Scahill, Klin, and Volkmar (1999) reported antidepressants were the most commonly used medications for individuals with ASD. Stimulant drugs affect the central nervous system and should be used with caution. The most widely prescribed stimulant is Ritalin. Adderall, a dextroamphetamine/amphetamine combination, may be a better choice because there is less likelihood of rebound (Waltz, 2002). Additionally, Waltz (2002) recommended that if stimulants are prescribed, they should be used as part of a multifactor treatment plan including behavior management.

Neuroleptics are used to treat severe mental illnesses. Haldol is the most familiar neuroleptic. This class of drugs affects dopamine production or absorption. Neuroleptics have been found to be beneficial in treating behavior problems in individuals with autism (Waltz, 2002). One study (Malone et al., 2002) reported Risperidone, a newer atypical neuroleptic, was effective for treatment of behavior problems in children with autism. Further, another study (McDougle, Kem, & Posey, 2002) revealed that Ziprasidone reduced aggression and irritability in children and adolescents with autism. One problem many people report with neuroleptics is weight gain. All medications must be carefully monitored, especially neuroleptics.

There are many other interventions for pervasive developmental disorders. It is not within the scope of this paper to examine them all; however, some others are worth briefly mentioning. Other treatment modalities include medical interventions, such as EKG and blood tests, alternative therapies, such as herbal regiments, anti-yeast diets, vitamins, and allergy treatments. Others include animal therapy, bodywork, and eye and vision therapies. See Mitzi Waltz's book, Autistic Spectrum Disorders: Understanding the Diagnosis & Getting Help for more information on alternative treatments.

How PDD Affects the Family

Having a child with PDD affects the entire family. Every parent has dreams for his/her child. When a parent hears *your child has PDD,* those dreams change. Sandy, mother of 5-year-old Tommy explains:

> I felt so guilty. Was it something I did or didn't do? I felt helpless, and I don't know what to do next. I worry about my son's future.

When a child is diagnosed with ASD, family members go through emotional upheaval much like a grieving process.. At first, parents may experience denial (this can't be true). During this stage, a parent may search diligently for a different diagnosis, one that can be *cured.* During the second phase, parents experience anger (I can't believe this is happening to me, why me) and may blame each other for their child's disability. The next stage is bargaining. When bargaining fails to get the desired results (a cure), individuals may feel hopeless, guilty, and sad. The result may be depression. Grandmother of 6-year-old Lee described her experience after Lee's initial diagnosis of PDD NOS:

> All I could see on the psychologist's report was PDD NOS and rule out MR. I had already started a college fund, and I thought I might as well forget it. My daughter and I cried all the way home from the hospital. I felt like a rock was lying on my chest. I also felt guilty. Why had I not noticed *something* was wrong?

The final stage in the grieving process is acceptance. When parents accept that their child has a disability, they can then take appropriate action, which may include trying different interventions and talking to other parents who have a child with an ASD. However, acceptance does not imply resignation; it means parents finally realize that their child has a *life-long disability*. Parents may go through the grief process over and over again, as their child negotiates each developmental milestone. Joining a support group can be invaluable during the entire process.

According to Myles and Simpson (1998), in addition to family members having to deal with the challenges of raising a child with a disability, they also may have to educate others, especially if their child is behaving inappropriately in public. Additionally, if there are other children in the family, parents have the added responsibility of helping them to not feel as if the child with PDD is getting all the attention.

According to Waltz (2002), discipline may be a problem for parents because behavior problems may be bigger and solving them more difficult. Waltz (2002) recommended discipline be positive and that punishment be based on the child experiencing consequences of an undesirable behavior. Additionally, parents must agree on disciplinary measures and present a united front.

Families who have a child with PDD may face additional challenges, such as financial burdens related to the disability, social isolation, and burnout. Family

discord may increase. For single parents, these problems are multiplied. Parenting classes, support groups, and family therapy can be invaluable resources.

It is crucial for both parents and teachers to keep in mind several important factors when working with a child who has PDD. First, when communicating with a child who has an ASD, be concise and clear, and make eye contact. Secondly, individuals with PDD like structure and familiar routines, and may need reassurance when routines are disrupted. Additionally, each child should be treated as an individual with unique talents. Further, parents and educators should work collaboratively toward goals that are best for the child. Consistency is key when dealing with a child who has PDD. Willey (2001) who has Asperger syndrome recommended finding support and that we learn to redefine "normal." Waltz (2002) stated that the best one can do is to work toward understanding your child, ask questions, and listening to the answers.

Discussion

An extensive review of the literature on pervasive developmental disorders/autistic spectrum disorders yielded inconclusive results regarding causality. Causes of PDD are unclear and still under investigation. One factor experts agree on is ineffective parenting does not cause PDD. However, future research should examine the role of biopsychosocial factors on pervasive developmental disorders. No research has examined the hypothesis that an individual may have a predisposition to PDD, much like depression or addiction,

and that the interaction of environmental factors and temperament may lead to PDD. Further, more research needs to be conducted on the association between ear infections and PDD, as well as, the contribution of genetic factors to developmental disorders.

In the areas of assessment and diagnosis for PDD, caution should be the guiding principle. No diagnosis should be based on any one test and clinicians need to consider culture and learning styles when conducting an evaluation. IDEA's exclusionary mandate definitely applies here; that is, clinicians need to make sure the child's disability is not the result of other factors, such as, central auditory processing dysfunction or environmental factors.

Researchers (Myles & Simpson, 1998; Turnbull et al., 2002) agree that early intervention and comprehensive programs produce more favorable outcomes. They agree that parents and educators working together contribute to better lives for individuals who have PDD. Further, transitional planning should begin early and include collaboration with community agencies and resources.

The mandates set forth under the Individuals with Disabilities Education Act are necessary but not sufficient. There is room for improvement. Teachers should be encouraged to try new and different approaches, instead of having to deal with restrictions imposed by school systems. Classes need to be smaller and provide more "hands-on" learning. Localities need to invest more revenue into

education. Additionally, in many instances, inclusion is still the exception rather than the rule, so inclusionary practices need to be monitored more closely.

Parents need to advocate for their children, and when parents are unable to do so, advocates should be available at the local level. For instance, in this writer's locality, the nearest advocacy personnel are 100 miles away. Parents need to be provided information, resources, and training, if necessary, on how to advocate for their child. Parents also need education and support for themselves, as well as, respite services. Additionally, the number of grandparents raising grandchildren has increased by over 30%. Further, grandparents often assist their children in caring for a grandchild with a disability. Therefore, grandparents play a vital role and need information, assistance, and support.

Assisting children with learning disabilities, PDD, or other disabilities is not a simple task. It requires coordination, collaboration, and dedication. Parents of children with PDD have a tremendous task before them, as do educators who teach these special children.

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Appendix A

Diagnostic Tools

From: Autistic Spectrum Disorders: Understanding The Diagnosis and Getting Help
Waltz, M. (2002)

CARS: Childhood Autism Rating Scale

The following items are a sample of the questions found on the Childhood Autism Rating Scale, by Eric Schopler, Dr. Robert Reichler, and Barbara Rochen Renner (Los Angeles: Western Psychological Services, 1993), also known as the CARS. This instrument is often used to evaluate young children who may have autistic spectrum disorders. Evaluators using the CARS rate the child on a scale from 1 to 4 in each of 15 areas.

Relating to People

Rating	Behavior
1	No evidence of difficulty or abnormality in relating to people. The child's behavior is appropriate for his or her age. Some shyness, fussiness, or annoyance at being told what to do may be observed, but not to an atypical degree.
1.5	(if between these points)
2	Mildly abnormal relationships. The child may avoid looking the adult in the eye, avoid the adult or become fussy if interaction is forced, be excessively shy, not be as responsive to the adult as is typical, or cling to parents somewhat more than most children of the same age.
2.5	(if between these points)
3	Moderately abnormal relationships. The child shows aloofness (seems unaware of adult) at times. Persistent and forceful attempts are necessary to get the child's attention at times. Minimal contact is initiated by the child.
3.5	(if between these points)
4	Severely abnormal relationships. The child is consistently aloof or unaware of what the adult is doing. He or she almost never responds or initiates contact with the adult. Only the most persistent attempts to get the child's attention have any effect.

Body Use

Rating	Behavior
1	Age-appropriate body use. The child moves with the same ease, agility, and coordination of a normal child of the same age.
1.5	(if between these points)
2	Mildly abnormal body use. Some minor peculiarities may be present, such as clumsiness, repetitive movements, poor coordination, or the rare appearance of more unusual movements.
2.5	(if between these points)
3	Moderately abnormal body use. Behaviors that are clearly strange or unusual for a child of this age may include strange finger movements, peculiar finger or body posturing, staring or picking at the body, self-directed aggression, rocking, spinning, finger-wiggling, or toe-walking.

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Rating	Behavior
3.5	(if between these points)
4	Severely abnormal body use. Intense or frequent movements of the type listed above are signs of severely abnormal body use. These behaviors may persist despite attempts to discourage them or involve the child in other activities.

Adaptation to Change

Rating	Behavior
1	Age-appropriate response to change. While the child may notice or comment on changes in routine, he or she accepts these changes without undue distress.
1.5	(if between these points)
2	Mildly abnormal adaptation to change. When an adult tries to change tasks, the child may continue the same activity or use the same materials.
2.5	(if between these points)
3	Moderately abnormal adaptation to change. The child actively resists changes in routine, tries to continue the old activity, and is difficult to distract. He or she may become angry and unhappy when an established routine is altered.
3.5	(if between these points)
4	Severely abnormal adaptation to change. The child shows severe reactions to change. If a change is forced, he or she may become extremely angry or uncooperative and respond with tantrums.

Listening Response

Rating	Behavior
1	Age-appropriate listening response. The child's listening behavior is normal and appropriate for age. Listening is used together with other senses.
1.5	(if between these points)
2	Mildly abnormal listening response. There may be some lack of response, or mild overreaction to certain sounds. Responses to sounds may be delayed, and sounds may need repetition to catch the child's attention. The child may be distracted by extraneous sounds.
2.5	(if between these points)
3	Moderately abnormal listening response. The child's responses to sounds vary; often ignores a sound the first few times it is made; may be startled or cover ears when hearing some everyday sounds.
3.5	(if between these points)
4	Severely abnormal listening response. The child overreacts and/or under reacts to sounds to an extremely marked degree, regardless of the type of sound.

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Verbal Communication

Rating	Behavior
1	Normal verbal communication, age and situation appropriate.
1.5	(if between these points)
2	Mildly abnormal verbal communication. Speech shows overall retardation. Most speech is meaningful; however, some echolalia or pronoun reversal may occur. Some peculiar words or jargon may be used occasionally.
2.5	(if between these points)
3	Moderately abnormal verbal communication. Speech may be absent. When present, verbal communication may be a mixture of some meaningful speech and some peculiar speech such as jargon, echolalia, or pronoun reversal. Peculiarities in meaningful speech include excessive questioning or preoccupation with particular topics.
3.5	(if between these points)
4	Severely abnormal verbal communication. Meaningful speech is not used. The child may make infantile squeals, weird or animal-like sounds, complex noises approximating speech, or may show persistent, bizarre use of some recognizable words or phrases.

This sample was used with permission from Western Psychological Services and the authors. The complete Childhood Autism Rating Scale is available to qualified professionals. Please write to:

Western Psychological Services
12031 Wilshire Boulevard
Los Angeles, CA 90025

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From: Autistic Spectrum Disorders: Understanding the Diagnosis and Getting Help
Waltz, M. (2002).

Diagnostic Checklist for Behavior-Disturbed Children (Form E-2)

Has this child been diagnosed before?

If so, what was the diagnosis?

Diagnosed by:

Where?

Instructions: You are being asked to fill out this questionnaire concerning your child in order to provide research information which will be helpful in learning more about the causes and types of behavior disturbances in children. Please pick the one answer you think is most accurate for each question. If you want to comment or add something about a question, add it right next to the question, if there is room. Or circle the number of the question, copy the number on the back of the questionnaire and write your comment there. Your additional comments are welcome, but even if you do add comments, please mark the printed question as well as you can. Remember, pick just one answer, and mark it with an "X," for each question.

It would be helpful if, on a separate sheet, you would write in any information about the child and his sisters or brothers which you think may be significant. (For example: Twins, living or dead; Behavior problems; IQ scores, if known).

USE AN "X" TO MARK ONE ANSWER FOR EACH QUESTION. DO NOT SKIP MAIN QUESTIONS. SUB-QUESTIONS (NOT ALONG LEFT MARGIN) MAY BE SKIPPED.

1. Present age of child:
   - ☐ 1. Under 3 years old
   - ☐ 2. Between 3 and 4 years old
   - ☐ 3. Between 4 and 5 years old
   - ☐ 4. Between 5 and 6 years old*
   - ☐ 5. Over 6 years old (Age: ____ years)
2. Indicate child's sex:
   - ☐ 1. Boy
   - ☐ 2. Girl
3. Indicate child's birth order and number of mother's other children:
   - ☐ 1. Child is an only child
   - ☐ 2. Child is first born of ____ children
   - ☐ 3. Child is last born of ____ children
   - ☐ 4. Child is middle born; ____ children are older and ____ are younger
   - ☐ 5. Foster child, or don't know

---

* This checklist is designed primarily for children 3 to 5 years old. If child is over 5, answer as well as you can by recall of the child's behavior.

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4. Were pregnancy and delivery normal?

- ☐ 1. Pregnancy and delivery both normal
- ☐ 2. Problems during both pregnancy and delivery
- ☐ 3. Pregnancy troubled; routine delivery
- ☐ 4. Pregnancy untroubled; problems during delivery
- ☐ 5. Don't know

5. Was the birth premature (birth weight under 5 lbs)?

- ☐ 1. Yes (about ___weeks early; ___lbs)
- ☐ 2. No
- ☐ 3. Don't know

6. Was the child given oxygen in the first week?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 3. Don't know

7. Appearance of child during first few weeks after birth:

- ☐ 1. Pale, delicate looking
- ☐ 2. Unusually healthy looking
- ☐ 3. Average, don't know, or other

8. Unusual conditions of birth and infancy (check only one number in left-hand column):

- ☐ 1. Unusual conditions
  Indicate which:
  ___blindness ___cerebral palsy ___birth injury
  ___seizures ___blue baby ___very high fever ___jaundice
  ___other
- ☐ 2. Twin birth (___identical ___fraternal)
- ☐ 3. Both 1 and 2
- ☐ 4. Normal, or don't know

9. Concerning baby's health in first 3 months:

- ☐ 1. Excellent health, no problems
- ☐ 2. Respiration (___frequent infections ___other)
- ☐ 3. Skin (___rashes ___infection ___allergy ___other)
- ☐ 4. Feeding (___learning to suck ___colic ___vomiting ___other)
- ☐ 5. Elimination (___diarrhea ___constipation ___other)
- ☐ 6. Several of above (indicate which: ___2 ___3 ___4 ___5)

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10. Has the child been given an electroencephalogram (EEG)?

- ☐ 1. Yes, it was considered normal
- ☐ 2. Yes, it was considered borderline
- ☐ 3. Yes, it was considered abnormal
- ☐ 4. No, or don't know, or don't know results

11. In the first year, did the child react to bright lights, bright colors, unusual sounds, etc.?

- ☐ 1. Unusually strong reaction (___pleasure ___dislike)
- ☐ 2. Unusually unresponsive
- ☐ 3. Average, or don't know

12. Did the child behave normally for a time before his abnormal behavior began?

- ☐ 1. Never was a period of normal behavior
- ☐ 2. Normal during first 6 months
- ☐ 3. Normal during first year
- ☐ 4. Normal during first 1 ½ years
- ☐ 5. Normal during first 2 years
- ☐ 6. Normal during first 3 years
- ☐ 7. Normal during first 4–5 years

13. (Age 4–8 months) Did the child reach out or prepare himself to be picked up when mother approached him?

- ☐ 1. Yes, or I believe so
- ☐ 2. No, I don't think he did
- ☐ 3. No, definitely not
- ☐ 4. Don't know

14. Did the child rock in his crib as a baby?

- ☐ 1. Yes, quite a lot
- ☐ 2. Yes, sometimes
- ☐ 3. No, or very little
- ☐ 4. Don't know

15. At what age did the child learn to walk alone?

- ☐ 1. 8–12 months
- ☐ 2. 13–15 months
- ☐ 3. 16–18 months
- ☐ 4. 19–24 months
- ☐ 5. 25–36 months
- ☐ 6. 37 months or later, or does not walk alone

16. Which describes the change from crawling to walking?

- ☐ 1. Normal change from crawling to walking
- ☐ 2. Little or no crawling, gradual start of walking
- ☐ 3. Little or no crawling, sudden start of walking
- ☐ 4. Prolonged crawling, sudden start of walking
- ☐ 5. Prolonged crawling, gradual start of walking
- ☐ 6. Other, or don't know

17. During the child's first year, did he seem to be unusually intelligent?

- ☐ 1. Suspected high intelligence
- ☐ 2. Suspected average intelligence
- ☐ 3. Child looked somewhat dull

18. During the child's first 2 years, did he like to be held?

- ☐ 1. Liked being picked up; enjoyed being held
- ☐ 2. Limp and passive on being held
- ☐ 3. You could pick child up and hold it only when and how it preferred
- ☐ 4. Notably stiff and awkward to hold
- ☐ 5. Don't know

19. Before age 3, did the child ever imitate another person?

- ☐ 1. Yes, waved bye-bye
- ☐ 2. Yes, played pat-a-cake
- ☐ 3. Yes, other (_____)
- ☐ 4. Two or more of above (which? ___1 ___2 ___3)
- ☐ 5. No, or not sure

20. Before age 3, did the child have an unusually good memory?

- ☐ 1. Remarkable memory for songs, rhymes, TV commercials, etc., in words
- ☐ 2. Remarkable memory for songs, music (humming only)
- ☐ 3. Remarkable memory for names, places, routes, etc.
- ☐ 4. No evidence for remarkable memory
- ☐ 5. Apparently rather poor memory
- ☐ 6. Both 1 and 3
- ☐ 7. Both 2 and 3

21. Did you ever suspect the child was very nearly deaf?

- ☐ 1. Yes
- ☐ 2. No

22. (Age 2–4) Is child "deaf" to some sounds but hears others?

- ☐ 1. Yes, can be "deaf" to loud sounds, but hear low ones
- ☐ 2. No, this is not true of him

23. (Age 2–4) Does child hold his hands in strange postures?

- ☐ 1. Yes, sometimes or often
- ☐ 2. No

24. (Age 2–4) Does child engage in rhythmic or rocking activity for very long periods of time (like on rocking-horse or chair, jumpchair, swing, etc.)?

- ☐ 1. Yes, this is typical
- ☐ 2. Seldom does this
- ☐ 3. Not true of him

25. (Age 2–4) Does child ever "look through" or "walk through" people, as though they weren't there?

- ☐ 1. Yes, often
- ☐ 2. Yes, I think so
- ☐ 3. No, doesn't do this

26. (Age 2–5) Does child have any unusual cravings for things to eat or chew on?

- ☐ 1. Yes, salt or salty foods
- ☐ 2. Yes, often chews metal objects
- ☐ 3. Yes, other (_____)
- ☐ 4. Yes, more than 2 above (which? _____)
- ☐ 5. No, or not sure

27. (Age 2–4) Does child have certain eating oddities, such as refusing to drink from a transparent container, eating only hot (or cold) food, eating only one or two foods, etc.?

- ☐ 1. Yes, definitely
- ☐ 2. No, or not to any marked degree
- ☐ 3. Don't know

28. Would you describe your child around 3 or 4 as often seeming "in a shell," or so distant and "lost in thought" that you couldn't reach him?

- ☐ 1. Yes, this is a very accurate description
- ☐ 2. Once in awhile he might possibly be like that
- ☐ 3. Not an accurate description

29. (Age 2–5) Is he cuddly?

- ☐ 1. Definitely, likes to cling to adults
- ☐ 2. Above average (likes to be held)
- ☐ 3. No, rather stiff and awkward to hold
- ☐ 4. Don't know

30. (Age 3–5) Does the child deliberately hit his own head?

- ☐ 1. Never, or rarely
- ☐ 2. Yes, usually by slapping it with his hand
- ☐ 3. Yes, usually by banging it against someone else's legs or head
- ☐ 4. Yes, usually by hitting walls, floor, furniture, etc.
- ☐ 5. Several of above (which? ___2 ___3 ___4)

31. (Age 3–5) How well physically coordinated is the child (running, walking, balancing, climbing)?

- ☐ 1. Unusually graceful
- ☐ 2. About average
- ☐ 3. Somewhat below average, or poor

32. (Age 3–5) Does the child sometimes whirl himself like a top?

- ☐ 1. Yes, does this often
- ☐ 2. Yes, sometimes
- ☐ 3. Yes, if you start him out
- ☐ 4. No, he shows no tendency to whirl

33. (Age 3–5) How skillful is the child in doing fine work with his fingers or playing with small objects?

- ☐ 1. Exceptionally skillful
- ☐ 2. Average for age
- ☐ 3. A little awkward, or very awkward
- ☐ 4. Don't know

34. (Age 3–5) Does the child like to spin things like jar lids, coins, or coasters?

- ☐ 1. Yes, often and for rather long periods
- ☐ 2. Very seldom, or never

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35. (Age 3–5) Does child show an unusual degree of skill (much better than normal child his age) at any of the following:

- ☐ 1. Assembling jigsaw or similar puzzles
- ☐ 2. Arithmetic computation
- ☐ 3. Can tell day of week a certain date will fall on
- ☐ 4. Perfect musical pitch
- ☐ 5. Throwing and/or catching a ball
- ☐ 6. Other (_____)
- ☐ 7. More than one of above (which? _____)
- ☐ 8. No unusual skill, or not sure

36. (Age 3–5) Does the child sometimes jump up and down gleefully when pleased?

- ☐ 1. Yes, this is typical
- ☐ 2. No, or rarely

37. (Age 3–5) Does child sometimes line things up in precise evenly spaced rows and insist they not be disturbed?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 3. Not sure

38. (Age 3–5) Does the child refuse to use his hands for an extended period of time?

- ☐ 1. Yes
- ☐ 2. No

39. Was there a time before age 5 when the child strongly insisted on listening to music on records?

- ☐ 1. Yes, insisted on only certain records
- ☐ 2. Yes, but almost any record would do
- ☐ 3. Liked to listen, but didn't demand to
- ☐ 4. No special interest in records

40. (Age 3–5) How interested is the child in mechanical objects such as the stove or vacuum cleaner?

- ☐ 1. Little or no interest
- ☐ 2. Average interest
- ☐ 3. Fascinated by certain mechanical things

41. (Age 3–5) How does the child usually react to being interrupted in what he is doing?

- ☐ 1. Rarely or never gets upset
- ☐ 2. Sometimes gets mildly upset; rarely very upset
- ☐ 3. Typically gets very upset

42. (Age 3–5) Will the child readily accept new articles of clothing (shoes, coats, etc.)?

- ☐ 1. Usually resists new clothes
- ☐ 2. Doesn't seem to mind, or enjoys them

43. (Age 3–5) Is child upset by certain things that are not "right" (like crack in the wall, spot on rug, books leaning in bookcase, broken rung on chair, pipe held and not smoked)?

- ☐ 1. Not especially
- ☐ 2. Yes, such things upset him greatly
- ☐ 3. Not sure

44. (Age 3–5) Does child adopt complicated "rituals" that make him very upset if not followed (like putting many dolls to bed in a certain order, taking exactly the same route between two places, dressing according to a precise pattern, or insisting that only certain words be used in a given situation)?

- ☐ 1. Yes, definitely
- ☐ 2. Not sure
- ☐ 3. No

45. (Age 3–5) Does child get very upset if certain things he is used to are changed (like furniture or toy arrangement, or certain doors which must be left open or shut)?

- ☐ 1. No
- ☐ 2. Yes, definitely
- ☐ 3. Slightly true

46. (Age 3–5) Is the child destructive?

- ☐ 1. Yes, this is definitely a problem
- ☐ 2. Not deliberately or severely destructive
- ☐ 3. Not especially destructive

47. (Age 3–5) Is the child unusually physically pliable (can be led easily; melts into your arms)?

- ☐ 1. Yes
- ☐ 2. Seems normal in this way
- ☐ 3. Definitely not pliable

48. (Age 3–5) Which single description, or combination of two descriptions, best characterizes the child?

- ☐ 1. Hyperactive, constantly moving, changes quickly from one thing to another
- ☐ 2. Watches television quietly for long periods
- ☐ 3. Sits for long periods
  For example, stares into space or plays repetitively with objects, without apparent purpose
- ☐ 4. Combination of 1 and 2
- ☐ 5. Combination of 2 and 3
- ☐ 6. Combination of 1 and 3

49. (Age 2–5) Does the child seem to want to be liked?

- ☐ 1. Yes, unusually so
- ☐ 2. Just normally so
- ☐ 3. Indifferent to being liked; happiest when left alone

50. (Age 3–5) Is child sensitive and/or affectionate?

- ☐ 1. Is sensitive to criticism and affectionate
- ☐ 2. Is sensitive to criticism, not affectionate
- ☐ 3. Not sensitive to criticism, is affectionate
- ☐ 4. Not sensitive to criticism nor affectionate

51. (Age 3–5) Is it possible to direct child's attention to an object some distance away or out a window?

- ☐ 1. Yes, no special problem
- ☐ 2. He rarely sees things very far out of reach
- ☐ 3. He examines things with fingers and mouth only

52. (Age 3–5) Do people consider the child especially attractive?

- ☐ 1. Yes, very good-looking child
- ☐ 2. No, just average
- ☐ 3. Faulty in physical appearance

53. (Age 3–5) Does the child look up at people (meet their eyes) when they are talking to him?

- ☐ 1. Never, or rarely
- ☐ 2. Only with parents
- ☐ 3. Usually does

54. (Age 3–5) Does the child take an adult by the wrist to use adult's hand (to open door, get cookies, turn on TV, etc.)?

- ☐ 1. Yes, this is typical
- ☐ 2. Perhaps, or rarely
- ☐ 3. No

55. (Age 3–5) Which set of terms best describes the child?

- ☐ 1. Confused, self-concerned, perplexed, dependent, worried
- ☐ 2. Aloof, indifferent, self-contented, remote

56. (Age 3–5) Is the child extremely fearful?

- ☐ 1. Yes, of strangers or certain people
- ☐ 2. Yes, of certain animals, noises or objects
- ☐ 3. Yes, of 1 and 2 above
- ☐ 4. Only normal fearfulness
- ☐ 5. Seems unusually bold and free of fear
- ☐ 6. Child ignores or is unaware of fearsome objects

57. (Age 3–5) Does he fall or get hurt in running or climbing?

- ☐ 1. Tends toward falling or injury
- ☐ 2. Average in this way
- ☐ 3. Never, or almost never, exposes self to falling
- ☐ 4. Surprisingly safe despite active climbing, swimming, etc.

58. (Age 3–5) Is there a problem in that the child hits, pinches, bites, or otherwise injures himself or others?

- ☐ 1. Yes, self only
- ☐ 2. Yes, others only
- ☐ 3. Yes, self and others
- ☐ 4. No, not a problem

59. At what age did the child say his first words (even if later stopped talking)?

- ☐ 1. Has never used words
- ☐ 2. 8–12 months
- ☐ 3. 13–15 months
- ☐ 4. 16–24 months
- ☐ 5. 2 years–3 years
- ☐ 6. 3 years–4 years
- ☐ 7. After 4 years old
- ☐ 8. Don't know

60. In the space below list child's first six words (as well as you can remember them).

61. (Before age 5) Did the child start to talk, then become silent again for a week or more?

- ☐ 1. Yes, but later talked again (age stopped___ duration___)
- ☐ 2. Yes, but never started again (age stopped___)
- ☐ 3. No, continued to talk, or never began talking

62. (Before age 5) Did the child start to talk, then stop, and begin to whisper instead, for a week or more?

- ☐ 1. Yes, but later talked again (age stopped___ duration___)
- ☐ 2. Yes, still only whispers (age stopped talking ___)
- ☐ 3. Now doesn't even whisper
  (age stopped talking ___ age stopped whispering ___)
- ☐ 4. No, continued to talk, or never began talking

63. (Age 1–5) How well could the child pronounce his first words when learning to speak, and how well could he pronounce difficult words between 3 and 5?

- ☐ 1. Too little speech to tell, or other answer
- ☐ 2. Average or below average pronunciation of first words ("wabbit," etc.), and also poor at 3 to 5
- ☐ 3. Average or below on first words, unusually good at 3–5
- ☐ 4. Unusually good on first words, average or below at 3–5
- ☐ 5. Unusually good on first words, and also at 3–5

64. (Age 3–5) Is the child's vocabulary (the number of things he can name or point to accurately) greatly out of proportion to his ability to "communicate" (to answer questions or tell you something)?

- ☐ 1. He can point to many objects I name, but doesn't speak or "communicate"
- ☐ 2. He can accurately name many objects, but not "communicate"
- ☐ 3. Ability to "communicate" is pretty good—about what you would expect from the number of words he knows
- ☐ 4. Doesn't use or understand words

65. When the child spoke his first sentences, did he surprise you by using words he had not used individually before?

- ☐ 1. Yes (Any examples? _____)
- ☐ 2. No
- ☐ 3. Not sure
- ☐ 4. Too little speech to tell

66. How did child refer to himself on first learning to talk?

- ☐ 1. "(John) fall down," or "Baby (or Boy) fall down."
- ☐ 2. "Mc fall down," or "I fall down"
- ☐ 3. "(He, Him, She, or Her) fall down"
- ☐ 4. "You fall down"
- ☐ 5. Any combination of a, b, and/or c
- ☐ 6. Combination of a and d
- ☐ 7. No speech or too little speech as yet

67. (Age 3–5) Does child repeat phrases or sentences that he has heard in the past (maybe using a hollow, parrot-like voice), what is said having little or no relation to the situation?

- ☐ 1. Yes, definitely, except voice not hollow or parrot-like
- ☐ 2. Yes, definitely, including peculiar voice tone
- ☐ 3. Not sure
- ☐ 4. No
- ☐ 5. Too little speech to tell

68. (Before age 5) Can the child answer a simple question like "What is your first name?" or "Why did Mommy spank Billy?"

- ☐ 1. Yes, can answer such questions adequately
- ☐ 2. No, uses speech, but can't answer questions
- ☐ 3. Too little speech to tell

69. (Before age 5) Can the child understand what you say to him, judging from his ability to follow instructions or answer you?

- ☐ 1. Yes, understands very well
- ☐ 2. Yes, understands fairly well
- ☐ 3. Understands a little, if you repeat and repeat
- ☐ 4. Very little or no understanding

70. (Before age 5) If the child talks, do you feel he understands what he is saying?

- ☐ 1. Doesn't talk enough to tell
- ☐ 2. No, he is just repeating what he has heard with hardly any understanding
- ☐ 3. Not just repeating—he understands what he is saying, but not well
- ☐ 4. No doubt that he understands what he is saying

71. (Before age 5) Has the child used the word "Yes?"

- ☐ 1. Has used "Yes" fairly often and correctly
- ☐ 2. Seldom has used "Yes," but has used it
- ☐ 3. Has used sentences, but hasn't used word "Yes"
- ☐ 4. Has used a number of other words or phrases, but hasn't used word "Yes"
- ☐ 5. Has no speech, or too little speech to tell

72. (Age 3–5) Does the child typically say "yes" by repeating the same question he has been asked? (*Example*: You ask "Shall we go for a walk, Honey?" and he indicates he does want to go by saying "Shall we go for a walk, Honey" or "Shall we go for a walk?")

- ☐ 1. Yes, definitely, does not say "Yes" directly
- ☐ 2. No, would say "Yes" or "OK" or similar answer
- ☐ 3. Not sure
- ☐ 4. Too little speech to say

73. (Before age 5) Has the child asked for something by using the same sentence you would use when you offer it to him? (*Example*: The child wants milk, so he says: "Do you want some milk?" or "You want some milk")

- ☐ 1. Yes, definitely (uses "You" instead of "I")
- ☐ 2. No, would ask differently
- ☐ 3. Not sure
- ☐ 4. Not enough speech to tell

74. (Before age 5) Has the child used the word "I"?

- ☐ 1. Has used "I" fairly often and correctly
- ☐ 2. Seldom has used "I," but has used it correctly
- ☐ 3. Has used sentences, but hasn't used the word "I"
- ☐ 4. Has used a number of words or phrases, but hasn't used the word "I"
- ☐ 5. Has used "I," but only where the word "you" belonged
- ☐ 6. Has no speech, or too little speech to tell

75. (Before age 5) How does the child usually say "No" or refuse something?

- ☐ 1. He would just say "No"
- ☐ 2. He would ignore you
- ☐ 3. He would grunt and wave his arms
- ☐ 4. He would use some rigid meaningful phrase (like "Don't want it!" or "No milk!" or "No walk!")
- ☐ 5. Would use phrase having only private meaning like "Daddy go in car"
- ☐ 6. Other, or too little speech to tell

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76. (Before age 5) Has the child used one word or idea as a substitute for another, for a prolonged time? (*Example*: always says "catsup" to mean "red," or uses "penny" for "drawer" after seeing pennies in a desk drawer)

- ☐ 1. Yes, definitely
- ☐ 2. No
- ☐ 3. Not sure
- ☐ 4. Too little speech to tell

77. Knowing what you do now, at what age do you think you could have first detected the child's abnormal behavior? That is, when did detectable abnormal behavior actually begin? (Under "A," indicate when you might have; under "B" when you did.)

		A	B
☐ 1.	In first 3 months		
☐ 2.	4–6 months		
☐ 3.	7–12 months		
☐ 4.	13–24 months		
☐ 5.	2 years–3 years		
☐ 6.	3 years–4 years		
☐ 7.	After 4th year		

78. Parents' highest educational level

		(Father)	(Mother)
1.	Did not graduate high school		
2.	High school graduate		
3.	Post high school tech. training		
4.	Some college		
5.	College graduate		
6.	Some graduate work		
7.	Graduate degree ( )		

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79. Indicate the child's nearest blood relatives, including parents, who have been in a mental hospital or who were known to have been seriously mentally ill or retarded. Consider parents, siblings, grandparents, uncles and aunts.

If none, check here: ___

	Relationship	Diagnosis, if known (Schizophrenia, Depressive, Other)
1.		
2.		
3.		
4.		
5.		

Form E2, Part 2

Please answer the following questions by writing "1" if Very True, "2" if True and "3" if False on the line preceding the question. Except for the first two questions, which pertain to the child before age 2, answer "Very True" (1) or "True" (2) if the statement described the child any time before his 10th birthday. If the statement is not particularly true of the child before age 10, answer "False" (3). *Remember:* 1 = Very True, 2 = True, 3 = False.

____ 80. Before age 2, arched back and bent head back, when held

____ 81. Before age 2, struggled against being held

____ 82. Abnormal craving for certain foods

____ 83. Eats unusually large amounts of food

____ 84. Covers ears at many sounds

____ 85. Only certain sounds seem painful to him

____ 86. Fails to blink at bright lights

____ 87. Skin color lighter or darker than others in family
(which: ___lighter ___darker)

____ 88. Prefers inanimate (nonliving) things

____ 89. Avoids people

____ 90. Insists on keeping certain object with him

____ 91. Always frightened or very anxious

____ 92. Inconsolable crying

____ 93. Notices changes or imperfections and tries to correct them

____ 94. Tidy (neat, avoids messy things)

____ 95. Has collected a particular thing (toy horses, bits of glass, etc.)

____ 96. After delay, repeats phrases he has heard

____ 97. After delay, repeats whole sentences he has heard

____ 98. Repeats questions or conversations he has heard, over and over, without variation

____ 99. Gets "hooked" or fixated on one topic (like cars, mops, death)

____ 100. Examines surfaces with fingers

____ 101. Holds bizarre pose or posture

____ 102. Chews or swallows nonfood objects

____ 103. Dislikes being touched or held

____ 104. Intensely aware of odors

____ 105. Hides skill or knowledge, so you are surprised later on

____ 106. Seems not to feel pain

____ 107. Terrified at unusual happenings

____ 108. Learned words useless to himself

____ 109. Learned certain words, then stopped using them

Please supply any additional information that you think may lead to understanding the cause or diagnosis of the child's illness.

Appendix B

Individualized Education Program (IEP)

Sample

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

SE-78
Working Draft___
Final IEP___

Student Name_____ Date ___/___/___ Page ___ of ___

Student ID Number_____ Grade_____ DOB ___/___/___ Age* _____

Disability(ies) (if identified) _____

Parent/Guardian Name_____

Home Address_____ Phone # (H) (____)_____

Lynchburg, VA _____ Phone # (W) (____)_____

Most recent eligibility date..... ____/____/____

Most recent re-evaluation date ..... ____/____/____

Next re-evaluation must occur before this date ..... ____/____/____

Date of IEP meeting..... ____/____/____

This IEP will be reviewed no later than this date..... ____/____/____

Date parent notified of IEP meeting..... ____/____/____

Date student notified of IEP meeting (if transition will be discussed)..... ____/____/____

Copy of IEP given to parent/student by (Name)_____ On (Date) ____/____/____

IEP Teacher/Manager_____ Phone Number (____)_____

PARTICIPANTS INVOLVED:
The list below indicates that the individual participated in the development of this IEP and the placement decision; it does not authorize consent. Parent or student (age 18 or older) consent is indicated on the " Prior Notice/Consent" page.

NAME OF PARTICIPANT	POSITION
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

***The student must be informed at least one year prior to turning 18 that the IDEA procedural safeguards (rights) transfer to him/her at age 18 and be provided with an explanation of those procedural safeguards.**

Date informed ____/____/____

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

FACTORS FOR IEP TEAM CONSIDERATION

Student Name _____ Date ___/___/___ Page _____ of _____

During the IEP meeting the following factors must be considered by the IEP team. Best practice suggests that the IEP team document that the factors were considered and any decision made relative to each. The factors are addressed in other sections of the IEP if not documented on this page. (for example: see Present Level of Educational Performance)

1. The strengths of the student and the concerns of the parents for enhancing the education of their child;

2. The results of the initial evaluation or most recent evaluation of the student including state and district-wide assessments:

3. The communication needs of the student;

4. The student's assistive technology devices and services needs;

5. In the case of a **student whose behavior impedes his or her learning or that of others**, consider, when appropriate, strategies, including positive behavioral interventions, strategies, and supports to address that behavior;

6. In the case of a **student with limited English proficiency**, consider the language needs of the child as such needs relate to the child's IEP;

7. In the case of a **student who is blind or has a visual impairment**, provide for instruction in Braille and the use of Braille unless the IEP team determines, after an evaluation of the student's reading and writing skills, needs, and appropriate reading and writing media (including an evaluation of the student's future needs for instruction in Braille or the use of Braille), that instruction in Braille or the use of Braille is not appropriate for the student; and

8. In the case of a **student who is deaf or hard of hearing**, consider the student's language and communication needs, opportunities for direct communications with peers and professional personnel in the student's language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the student's language and communication mode.

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

PRESENT LEVEL OF EDUCATIONAL PERFORMANCE

Student Name_____ Date___/___/___ Page ___of___

The Present Level of Educational Performance describes the effect of the student's disability upon the student's involvement and progress in the general curriculum and area(s) of need. This includes the student's performance in academic areas (reading, math, communication, etc.) and non-academic areas (behavior, social skills, daily life activities, mobility, extra-curricular activities, etc.) in objective terms. Test scores, if appropriate, should be self-explanatory or an explanation should be included. For preschool students this section should include how the student's disability affects the student's participation in appropriate activities. **There should be a direct relationship between the present level of educational performance and the other components of the IEP.**

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LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

PRESENT LEVEL OF EDUCATIONAL PERFORMANCE, Continued
& DIPLOMA STATUS

Student Name_____ Date ___/___/___ Page ___of___

Present Level of Educational Performance, continued.

DIPLOMA STATUS: Discuss annually beginning at age 14, or younger. This student is a candidate for a:

[ ] Standard Diploma
[ ] Advanced Studies Diploma
[ ] Certificate of Program Completion
[ ] GED (General Educational Development) Certificate (only for those who meet requirements of the GED)
[ ] Not discussed at this time
[ ] Modified Standard Diploma*
[ ] Special Diploma

Projected Graduation/Exit Date: _____

COMMENTS:

NOTE: Special education and related services end upon receiving a Standard Diploma or Advanced Studies Diploma. If the student receives a Modified Standard Diploma, Special Diploma, Certificate of Program Completion, or a GED Certificate, the student remains entitled to a free appropriate public education through age 21.

* Eligibility and participation in the Modified Standard Diploma program is determined by the IEP team and the student, where appropriate, at any point after the student's eighth grade year.

➢ **Is secondary transition being addressed? ___No ___Yes**

If yes, complete "Secondary Transition" pages before developing measurable annual goals.

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)
GOALS/OBJECTIVES

Student Name _____ Date ___/___/___ Page ___of___

Area of Need _____

Annual Goal # ____: _____

Evaluation Schedule: _____

Evaluation Criteria: _____

Evaluation Method: _____

☐ Classroom Participation ☐ Checklist ☐ Classwork ☐ Written reports ☐ Homework
☐ Observation ☐ Special Project ☐ Tests and Quizzes ☐ LCS Six-Weeks SOL Assessment
☐ Norm-referenced test _____ ☐ Criterion-referenced test _____
☐ Other (list) _____

Relationship to the General Education Curriculum _____

Date of Progress Report m/d/y								
Progress Code								

Progress on this goal will be reported at the end of each marking period using the following codes:

SP – The student is making sufficient progress to achieve this annual goal within the duration of this IEP
ES – The student demonstrates emerging skill but may not achieve this goal within the duration of this IEP
IP – The student has demonstrated insufficient progress to meet this annual goal and may not achieve this goal within the duration of this IEP
NI – The student has not been provided instruction on this goal
M – The student has mastered this annual goal

Short Term Objective: _____

Evaluation Schedule: _____

Evaluation Criteria: _____

Evaluation Method: _____

Notes: _____

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LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)
OBJECTIVES (continued)

Student Name_____ Date___/___/___ Page ___of___

Area of Need_____

Annual Goal # ____: _____

Short Term Objective: _____

Evaluation Schedule: _____

Evaluation Criteria: _____

Evaluation Method: _____

Notes: _____

Short Term Objective: _____

Evaluation Schedule: _____

Evaluation Criteria: _____

Evaluation Method: _____

Notes: _____

Short Term Objective: _____

Evaluation Schedule: _____

Evaluation Criteria: _____

Evaluation Method: _____

Notes: _____

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LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

ACCOMMODATIONS/MODIFICATIONS

Student Name_____ Date___/___/___ Page ___of___

This student will be provided access to the general education, special education, other school services and activities including non-academic activities and extracurricular activities, and education related settings:

___ with no accommodations/modifications

___ with the following accommodations/modifications

Accommodations/modifications provided as part of the instructional and testing/assessment process will allow the student equal opportunity to access the curriculum and demonstrate achievement. Accommodations/modifications also provide access to non-academic and extracurricular activities and educationally related settings. Accommodations/modifications based solely on the potential to enhance performance beyond providing equal access are inappropriate.

Accommodations may be in, but not limited to, the areas of time, scheduling, setting, presentation and response. The impact of any modifications listed should be discussed. This includes the earning of credits for graduation.

ACCOMMODATIONS/MODIFICATIONS (please list, as appropriate)

Accommodation(s)/Modification(s)	Frequency	Location	Duration m/d/y to m/d/y

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

ACCOMMODATIONS/MODIFICATIONS, Continued
PARTICIPATION IN STATE AND DISTRICT-WIDE ASSESSMENTS

Student Name_____ Date___/___/___ Page ___of___

Accommodation(s)/Modification(s)	Frequency	Location	Duration m/d/y to m/d/y

STATE AND DISTRICT-WIDE ASSESSMENTS

This student's participation in state or district-wide assessments must be considered and discussed. During the duration of this IEP:

- Will the student be at an age or a grade level for which the student is eligible to participate in a state or district-wide assessment? ___ Yes
- Will the student be enrolled in a course for which there is a SOL End-of-Course test or district-wide assessment? ___ Yes
- Will the student be participating in a SOL remediation recovery program? or ___ Yes
- Will the student need to take a state assessment as a requirement to earn a Modified Standard Diploma, Standard Diploma, or Advanced Studies Diploma? ___ Yes

If Yes to any of the above, check the appropriate assessment(s).

___ State Assessments
___ SOL Assessments and retake (SOL)
___ Virginia Alternate Assessment (VAAP)
___ Virginia State Assessment Program (Stanford 9)
___ Literacy Passport Tests (LPT)

___District-wide Assessments (list)
_____
_____
_____
_____

Attach the identified assessment page(s), which will document the decisions made about participation and any needed accommodations and/or modifications.

PRIOR NOTICE/CONSENT

Student Name_____ Date___/___/___ Page ___of___

PRIOR NOTICE OF IEP AND PLACEMENT DECISION

The school division proposes to implement this IEP and the placement decision as written. This proposed IEP and placement will allow the student to receive a free appropriate public education in the least restrictive environment. This decision is based upon a review of current records, current assessments and the student's performance as documented in the Present Level of Educational Performance. Other options considered, if any, and the reason for their rejection are attached, or can be found in the Placement Decision section of this IEP. Additionally, other factors, if any, that are relevant to this proposal are attached. When the parent(s) and adult student were notified of the meeting to develop this IEP, they were provided a copy of the procedural safeguards that explains their rights. If you, the parent(s) and adult student, need another copy of the procedural safeguards or need assistance in understanding this information please contact _____ at (___) _____ or e-mail _____ or _____ at (___) _____ or e-mail _____.

___ Parent(s) initials here indicate that the parent(s) has read the above prior notice and attachments, if any, before giving permission to implement this IEP and the placement decision.

PARENT/ADULT STUDENT CONSENT: Indicate your response by checking the appropriate space and sign below.

___ I give permission to implement this IEP and the placement decision.

___ I do not give permission to implement this IEP and the placement decision.

_____ ___/___/___
Parent Signature or Adult Student Signature (if appropriate) Date

TRANSFER OF RIGHTS AT THE AGE OF MAJORITY (age 18):

Indicate the date that the student and parent were informed of the transfer of parental rights under IDEA to the adult student at the age of 18. This must occur at least one year prior to the age of 18.

_____ _____
Date School Official Signature

I was informed of the parental rights under IDEA and that these rights transfer to me at age 18.

_____ _____
Date Student Signature

I was informed of the parental rights under IDEA that transfer to my child at age 18.

_____ _____
Date Parent Signature

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)
Medicaid Students

Student Name _____ Date ___/___/___ Page ___ of ___

Student ID Number _____ Medicaid # _____ Grade _____

DOB ___/___/___ Age* _____ Disability(ies) (if identified) _____

Parent/Guardian Name _____

Home Address _____ Phone # (H) (____)_____

Lynchburg, VA _____ Phone # (W) (____)_____

Most recent eligibility date..... ____/____/____

Most recent re-evaluation date ..... ____/____/____

Next re-evaluation must occur before this date ..... ____/____/____

Date of IEP meeting..... ____/____/____

This IEP will be reviewed no later than this date..... ____/____/____

Date parent notified of IEP meeting..... ____/____/____

Date student notified of IEP meeting (if transition will be discussed)..... ____/____/____

Copy of IEP given to parent/student by (Name)_____ On (Date)____/____/____

IEP Teacher/Manager_____ Phone Number (____)_____

PARTICIPANTS INVOLVED:
The list below indicates that the individual participated in the development of this IEP and the placement decision; it does not authorize consent. Parent or student (age 18 or older) consent is indicated on the " Prior Notice/Consent" page.

NAME OF PARTICIPANT	POSITION

For Medicaid Students Only – Required for Billable Services

Physician Signature _____ Physician Name _____

Date ____/____/____ Phone (____) _____ Medicaid Discharge Plan/Disposition _____

***The student must be informed at least one year prior to turning 18 that the IDEA procedural safeguards (rights) transfer to him/her at age 18 and be provided with an explanation of those procedural safeguards.** **Date informed** ____/____/____

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

SERVICES – LEAST RESTRICTIVE ENVIRONMENT – PLACEMENT

Student Name_____ Date___/___/___ Page ___of___

Least Restrictive Environment (LRE)

When discussing least restrictive environment and placement options, the following must be considered:

- To the maximum extent appropriate, the student is educated with children without disabilities.
- Special classes, separate schooling or other removal of the student from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.
- The student's placement should be as close as possible to the child's home and unless the IEP of the student with a disability requires some other arrangement, the student is educated in the school that he or she would attend if he or she did not have a disability.
- In selecting the LRE, consideration is given to any potential harmful effect on the student or on the quality of services that he/she needs.
- The student with a disability is not removed from education in age-appropriate regular classrooms solely because of needed modifications in the general curriculum.

Free Appropriate Public Education (FAPE)

When discussing FAPE for this student, it is important for the IEP team to remember that FAPE may include, as appropriate:

- Educational Programs and Services
- Proper Functioning of Hearing Aids
- Assistive Technology
- Transportation
- Nonacademic and Extracurricular Services and Activities
- Physical Education
- Extended School Year Services
- Length of School Day

SERVICES: Identify the service(s), including frequency, duration and location, that will be provided to or on behalf of the student in order for the student to receive a free appropriate public education (see above). These services are the special education services and as necessary, the related services, supplementary aids and services, assistive technology, supports for personnel, accommodations and/or modifications* and extended school year services* the student will receive that will address area(s) of need as identified by the IEP team. Address any needed transportation and physical education services including accommodations and/or modifications.

Service(s)	Frequency	Location	Duration m/d/y to m/d/y

*These services are listed on the "Accommodations/Modifications" page and "Extended School Year Services" page, as needed.

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

SERVICES – LEAST RESTRICTIVE ENVIRONMENT – PLACEMENT, Continued

Student Name_____ Date___/___/___ Page ___of___

Service(s) cont.	Frequency	Location	Duration m/d/y to m/d/y

PLACEMENT

The team may consider placement options in conjunction with discussing any needed supplementary aids and services, accommodations/ modifications, assistive technology, and supports for school personnel. In considering the placement continuum options, check those the team discussed. Then, describe the placement selected in the **PLACEMENT DECISION** section below. Determination of LRE and placement may be one or a combination of options along the continuum.

Placement Continuum Options Considered:

Instruction Provided in:

___regular class(es)
(includes integrated settings)
___special class(es)

Special School:
___public day school
___private day school
___state operated program
___private residential facility

___home based instruction
___hospital
___other (describe):

PLACEMENT DECISION:

Based upon identified services and the consideration of least restrictive environment (LRE) and placement continuum options, describe in the space below the placement. Additionally, summarize the discussions and decision around LRE and placement. This must include an explanation of why the student **will not** be participating with students without disabilities in the general education class(es), programs, and activities. Attach additional pages as needed.

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LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

PRESENT LEVEL OF EDUCATIONAL PERFORMANCE, Continued

Student Name_____ Date___/___/___ Page ___of___

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

SECONDARY TRANSITION

Student Name_____ Date___/___/___ Page ___of___

TRANSITION – COURSE OF STUDY
(Beginning at age 14 or younger)

Describe the focus of the student's course of study (i.e., specify the educational courses and experiences in school and the community that will assist the student in achieving his/her post school goals). For students pursuing a modified standard diploma, consider the student's need for occupational readiness, including courses to prepare the student as a career and technical education program completer.

_____
_____
_____
_____
_____

TRANSITION SERVICES
(Beginning at age 16 or younger)

1. Desired Outcomes – POSTSECONDARY EMPLOYMENT (including integrated or supported employment)
_____

   - Is a functional vocational evaluation needed? ___yes ___no
     If yes, describe: _____
     _____
   - Is specially designed instruction needed? ___yes ___no
     If yes, describe (make sure the IEP addresses this need through goals, services, etc.):

2. Desired Outcomes – CAREER AND TECHNICAL EDUCATION _____
_____

   - Is specially designed instruction needed? ___yes ___no
     If yes, describe (make sure the IEP addresses this need through goals, services, etc.):

3. Desired Outcomes – POSTSECONDARY EDUCATION (including continuing and adult education)_____
_____

   - Is specially designed instruction needed? ___ yes ___ no
     If yes, describe (make sure the IEP addresses this need through goals, services, etc.):

4. Desired Outcomes – INDEPENDENT LIVING_____
_____

   - Is specially designed instruction needed? ___yes ___no
     If yes, describe (make sure the IEP addresses this need through goals, services, etc.):

5. Desired Outcomes – COMMUNITY PARTICIPATION_____
_____

   - Is specially designed instruction needed? ___yes ___no
     If yes, describe (make sure the IEP addresses this need through goals, services, etc.):

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

SECONDARY TRANSITION INTERAGENCY RESPONSIBILITIES & NEEDED LINKAGES

Student Name_____ Date___/___/___ Page ___of___

1. To assist in achieving post-secondary employment outcomes or goals, the student will be referred to the following agency(ies) or organization(s):

AGENCY/ORGANIZATION PERSON RESPONSIBLE FOR REFERRAL

_____

_____

Reason For Referral Including Requested Service(s):_____

_____

_____

2. To assist in achieving career and technical education outcomes or goals, the student will be referred to the following agency(ies) or organization(s):

AGENCY/ORGANIZATION PERSON RESPONSIBLE FOR REFERRAL

_____

_____

Reason For Referral Including Requested Service(s): _____

_____

_____

3. To assist in achieving post-secondary education outcomes or goals, the student will be referred to the following agency(ies) or organization(s):

AGENCY/ORGANIZATION PERSON RESPONSIBLE FOR REFERRAL

_____

_____

Reason For Referral Including Requested Service(s): _____

_____

_____

4. To assist in achieving independent living outcomes or goals, the student will be referred to the following agency(ies) or organization(s):

AGENCY/ORGANIZATION PERSON RESPONSIBLE FOR REFERRAL

_____

_____

Reason For Referral Including Requested Service(s): _____

_____

_____

5. To assist in achieving community participation outcomes or goals, the student will be referred to the following agency(ies) or organization(s):

AGENCY/ORGANIZATION PERSON RESPONSIBLE FOR REFERRAL

_____

_____

Reason For Referral Including Requested Service(s): _____

_____

_____

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

EXTENDED SCHOOL YEAR SERVICES (ESY)

Student Name_____ Date___/___/___ Page ___of___

Summarize the IEP team's discussions and decision about ESY:

If ESY services are to be provided, identify which goals in the current IEP will be addressed by the ESY services:

Identify the Extended School Year services needed to meet these goals:

ESY Service(s)	Frequency	Location	Duration m/d/y to m/d/y

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

LITERACY PASSPORT TESTS (LPT)

Student Name_____ Date___/___/___ Page ___of___

Complete this page for those students who fall within the LPT requirements in the *Regulations Establishing Standards for Accrediting Public Schools in Virginia.*

PARTICIPATION IN THE LPT

If the student is participating in the LPT, list the accommodation(s) and/or modification(s) that will be made based upon those the student generally uses during classroom instruction and assessment. For the accommodations and/or modifications that may be considered for this student, refer to the "Accommodations/Modifications" page of the IEP and the LPT guidelines adopted by the Virginia Board of Education.

The student will participate in the following LPT tests (check):

LITERACY PASSPORT TESTS	ACCOMMODATIONS MODIFICATIONS	If YES, List Accommodation(s) And/or Modification(s) by Test.
___Reading Comprehension Test ___/___/___Date Passed	___Yes ___No	
___Writing Test ___/___/___Date Passed	___Yes ___No	
___Mathematics Test ___/___/___Date Passed	___Yes ___No	

Mark any nonstandard administrations with an asterisk*. A student with a disability who has passed an LPT test utilizing any accommodation including a non-standard accommodation has passed for all purposes.

EXPLANATION FOR NON-PARTICIPATION AND HOW THE STUDENT WILL BE ASSESSED

If the student has postponed taking any part of the LPT or is exempted from taking the LPT, describe in the space below the reasons for the postponement or exemption, and how the student will be assessed in these areas.

NOTES: If a student postpones taking one or more of the literacy tests, it will decrease the student's opportunities to take and pass the tests. In order for a student to receive a Standard Diploma or Advanced Studies Diploma, the student must achieve passing scores on all three of the literacy tests according to the timeframe for certain students in the *Regulations Establishing Standards for Accrediting Public Schools in Virginia.*

Any decision to exempt the student from participating in the Literacy Passport Tests must be reviewed at least annually by the IEP team. Students exempted from participating in the Literacy Passport Tests will not be able to receive a Standard Diploma or Advanced Studies Diploma.

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

VIRGINIA STATE ASSESSMENT PROGRAM (VSAP) – STANFORD 9

Student Name_____ Date___/___/___ Page ___of___

As a ___4th, ___6th, ___9th grader this student is eligible to participate in the VSAP, the Stanford 9.

PARTICIPATION IN THE VSAP

If the student is participating in all or any part of the Stanford 9, list the accommodation(s) and/or modification(s) that will be made based upon those the student generally uses during classroom instruction and assessment. For the accommodations and/or modifications that may be considered for this student, refer to the "Accommodations/Modifications" page of the IEP and the guidelines adopted by the Virginia Board of Education. The student will participate in the following Stanford 9 subtest(s) (check):

TEST/SUBTEST	ACCOMMODATIONS MODIFICATIONS	If YES, List Accommodation(s) and/or Modification(s) by Subtest
READING ___Reading Vocabulary	___Yes ___No	
___Reading Comprehension	___Yes ___No	
MATHEMATICS ___Problem Solving	___Yes ___No	
___Procedures	___Yes ___No	
LANGUAGE ___Pre-writing	___Yes ___No	
___Composing	___Yes ___No	
___Editing	___Yes ___No	
SCIENCE (LOCAL OPTION) ___Science	___Yes ___No	
SOCIAL STUDIES (LOCAL OPTIONS) ___Social Studies	___Yes ___No	

NOTE: Mark any nonstandard administration with an asterisk*. These test scores will be reported as scores that result from a nonstandard administration of the test.

EXPLANATION FOR NON-PARTICIPATION AND HOW THE STUDENT WILL BE ASSESSED

For any test/subtest not checked, explain in the space below why the student **will not** be participating in this assessment, the impact relative to promotion or graduation, and how the student will be assessed in these areas:

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LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

VIRGINIA'S STANDARDS OF LEARNING ASSESSMENTS (SOL)
VIRGINIA ALTERNATE ASSESSMENT PROGRAM (VAAP)

Student Name_____ Date___/___/___ Page ___of___

PARTICIPATION IN THE SOL ASSESSMENTS

For the student who will be **(1)** in a grade level for which the student is eligible to participate in the SOL Assessment; **(2)** enrolled in a course for which there is an SOL end-of-course test; **(3)** participating in a remediation recovery program **or (4)** needs to take a SOL Assessment as a requirement to earn a Modified Standard Diploma, Standard Diploma or Advanced Studies Diploma, **list each test below**. Next determine if the student will participate in the SOL test and then list the accommodation(s) and/or modification(s) that will be made based upon those the student generally uses during classroom instruction and assessment. For the accommodations and/or modifications that may be considered, refer to "Accommodations/Modifications" page of the IEP and the Virginia Board of Education's guidelines.

SOL TESTS	PARTICIPATION	ACCOMMODATIONS MODIFICATIONS	If YES, List Accommodation(s) And/or Modification(s) by Test
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	

Mark any nonstandard administration with an asterisk*. These test scores will be reported as scores that result from a nonstandard administration. A student with a disability who has passed an SOL assessment utilizing any accommodation including a non-standard accommodation has passed for all purposes.

EXPLANATION FOR NON-PARTICIPATION AND HOW THE STUDENT WILL BE ASSESSED

If **no** is checked for any test, explain in the space below why the student **will not** participate in this test, the impact relative to promotion or graduation, and how the student will be assessed in these areas.

NOTE: The numeracy test (SOL Math 8 test) and literacy test (SOL English 8–Reading Research and Literature test) are requirements for the modified standard diploma. If the IEP team decides to postpone the student's participation in either of these tests, or postpones the student's retake of an end-of-course test that is a requirement to earn a Standard Diploma or Advanced Studies Diploma, then the student's opportunities to take and pass these tests will be decreased.

PARTICIPATION IN THE VIRGINIA ALTERNATE ASSESSMENT PROGRAM (VAAP)

Once the IEP team determines that the student will **not** participate any of the four core SOL tests (English, math, science, history/social science) or the SOL test will **not** be postponed (see note above), the student must be considered for participation in the Virginia Alternate Assessment Program (VAAP). However, the student must meet the VAAP participation criteria.

Does the student meet the criteria for the VAAP? ____ yes ____ no . If YES, the student will participate in the VAAP.

If the student meets all criteria except the age requirement, state the school year the student will participate in the VAAP. _____

If the criteria are not met, determine and document above how the student will participate in the SOL assessment program.

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LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

DISTRICT-WIDE ASSESSMENT(S)

Student Name_____ Date___/___/___ Page ___of___

PARTICIPATION IN DISTRICT-WIDE ASSESSMENTS

For the student who will be in a grade level or at an age for which the student is eligible to participate in a district–wide assessment, **list each district-wide assessment below**. Next determine if the student will participate in the assessment and then list the accommodation(s) and/or modification(s) that will be made based upon those the student generally uses during classroom instruction and assessment. For the accommodations and/or modifications that may be considered, refer to "Accommodations/Modifications" page of the IEP.

ASSESSMENT	PARTICIPATION	ACCOMMODATIONS MODIFICATIONS	If YES, List Accommodation(s) And/or Modification(s) by Assessment
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	
	___Yes ___No	___Yes ___No	

Mark any nonstandard administration with an asterisk*.

EXPLANATION FOR NON-PARTICIPATION AND HOW THE STUDENT WILL BE ASSESSED

If **no** is checked for any test, explain in the space below why the student **will not** participate in this test, the impact relative to promotion or graduation, and how the student will be assessed in these areas.

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PLACEMENT DECISION, Continued

PRIOR NOTICE, Continued

Student Name_____ Date___/___/___ Page ___of___

PRIOR NOTICE, Continued

Describe other options considered and the reasons for their rejection:

List other factors that are relevant to this proposal:

LYNCHBURG CITY SCHOOLS
INDIVIDUALIZED EDUCATION PROGRAM (IEP)

PRIOR NOTICE – Refusal(s)

Student Name_____ Date___/___/___ Page ___of___

After consideration we refuse to:

Reasons for the refusal(s):

Description of each evaluation procedure, test, record, or report used as a basis for the refusal(s):

Description of any options considered and the reasons why those options were rejected:

Description of any other factors which are relevant to the refusal(s):

NOTE: When the parent(s) and adult student were notified of the meeting to develop this IEP, they were provided a copy of the procedural safeguards that explains their rights. If you, the parent(s) and adult student, need another copy of the procedural safeguards or need assistance in understanding this information please contact _____ at
(___) _____ or e-mail _____ or _____ at
(___) _____ or e-mail _____.

Appendix C

Resources

Legal services: agencies, organizations, people

[| |]

International and USA

The Council of Parent Attorneys and Advocates has a page of state (and some) special education agencies and on-line court decisions

FindLaw lists extensive legal resources organized by state (and US Federal and international), including links to attorneys, laws, and consultants

Open Directory: Reference: Education: Special Education: Laws lists (mostly USA) attorneys, law firms, and legal resources

We Will Prevail is a support group to help parents or educational guardians seeking funding for special education or disability services

Canada

Lindsay Moir, at Comhnadh Consulting, 92 Cumberland Crescent, London, , Canada. N5X 1B6, (519)660-0493, l.moir@sympatico.ca

Danielle Renaud, 45-30 Doon Dr., London, N5X 3X2. "I consult to families and to schools regarding educational and behavioural problems. I also help parents to understand and to advocate for their children in terms of special education service provision." DRenaud@fanshawec.on.ca

USA

See also the listings

Association of Trial Lawyers of America

Directory of Legal and Advocacy Resources from Wrightslaw. A far more extensive list than what's included here.

Educational Law Firms (from Teach-nology)

National Association of Child Advocates lists advocates and advocacy organizations. 1522 K Street, NW, Suite 600, Washington D.C. 20005-1202, (202)289-0777, fax (202)289-0776

National Information Center for Children and Youth with Disabilities lists state agencies, government officials, advocacy organizations. They will give individual referrals, call (800)695-0285.

Parent Training and Information lists training, advocacy, and support organizations by state

Federation for Children with Special Needs, Boston, , a local organization that includes national

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resources and good information links. Free phone consults, (800)331-0688.

Parent Advocacy Coalition for Educational Rights (PACER) has both Minnesota and national information, 4826 Chicago Avenue South, Minneapolis 55417-1098, (612)827-2966; (612)827-7770, TDD (800)53-PACER (in MN)

Protection and Advocacy Services has links to advocacy organizations in the USA

Special Needs Advocate and Attorney Directory from Education-A-Must Inc.

USA by state

See also the USA listings

The Office of Advocacy for Autistic Children is a advocacy service that is willing to provide free telephone consultation. Contact Mike Robinson, Peace4Mikey@prodigy.com, (916)863-6037

Sarit Anam, Esq. is the parent of two special needs children. 20301 Ventura Blvd. #126, Woodland Hills 91364, Tel: (818)992-5770, Cell: (818)253-5305, Email sarit@saritlaw.com.

Sherman and Ziegler, Washington Mutual Bank Building, 2740 Van Ness Ave, Suite 300, San Francisco 94109, (415)924-1300, email: ASpecialEdLawyer@aol.com. Specializing in special education law and autism spectrum.

ACE2000, Advocacy for Children's Education, 1220 L Street NW, Suite 750, Washington 20005, Phone: (202)742-2050, Contact: Michelle L. Barker, English or Spanish, email: ACEDiamante@aol.com

Dorene Philpot, Attorney at Law, 156 E. Market St., Suite 200, Indianapolis 46204, (317)486-4578

Massachusetts Legal Services Programs, 37 Friend St., Lynn 01902, (781)599-7730

Sussan & Greenwald represents families in . Also a good source for special education legal information.

Blair McLaughlin, Law Office of Robert W. Ottinger, 11 John Street, Suite 407, New York 10038, phone: (212)608-4848, fax: (212)608-4383

The Family Resource Network, Oneonta

Parent Advocacy Services for Students (PASS), 11 White Spruce Circle, Commack 11725. Phone: (631)543-5751, e-mail: kimnordman@hotmail.com

Power Advocates, Western

Nessa G. Siegel, Co., L.P.A., 4070 Mayfield Road, Cleveland 44121, (216)291-1300, Fax (216) 291-9622

Lynne Z. Petkovic M.Ed., Education Advocate and Consultant, 22550 Westchester Road, Shaker Heights 44122, (216)752-7592, lpetkovic@aol.com

Oklahoma Disability Law Center, inc. City Office, (405)525-7755 (V/TDD), (800)880-7755 (V/TDD), Tulsa Office (918)743-6220 (V/TDD), (800)226-5883 (V/TDD)

Jonathan S. Corchnoy, Esquire, 1515 Market Street, Suite 2005, Philadelphia 19102. PA: (215)266-7872, NJ: (856)308-3330. Fax: (856)783-3330. E-mail: gpvanguard@hotmail.com. "I am the father of an 8 year old child diagnosed with PDD/NOS and ADHD, which keeps me particularly in tune with educational developments in the field. I have successfully represented parents within the Philadelphia School District; Camden County, NJ; and Charter Schools within Philadelphia County."

Parents Exchange provides help to families in , 102 East Mermaid Lane, Philadelphia PA 19118, (215)242-9501, (215)247-4229 (fax)

This page is rsaffran.tripod.com/legal.html
Write to me with your contact information to add, remove, or update a listing.

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Web Sites

http://www.autism-resourc ces.com/	autism resources
http://www.autism.com/ari/	autism research institute
http://www.isn.net/~ivpsy/auulink.htm	autism related sites world-wide
http://www.udel.edu/bkirby/asperger/	information on Asperger's Syndrome
http://members.aol.com/certvan/index.htm	mother's story of her autistic child
http://www.naic.org/splash.htm	National Association of Insurance
http://www.feat.org	Families for early autism treatment
http://www.edu.drake.edu/rc/sp_ed_top.html	Spec. Ed. And Disabilities Resources

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Person with Autism or Asperger's Syndrome. London: National Autism Society, 1991.

ıg, Lorna. *Autistic Spectrum Disorders: A Guide to Diagnosis*. London: National stic Society, 1993. This diagnostic guide is also available on tape.

Books by adults with ASDs

Jesssica Kingsley Publishers, a specialty publishing company, has published many books by people with ASDs. Its catalog is online at *http://www.jessicakingsley.com*.

Gerland, Gunilla. *A Real Person: Life on the Outside*. London: Souvenir Press, 1997.

Grandin, Temple. *Thinking in Pictures, and Other Reports from My Life with Autism*. New York: Vintage Books, 1996.

Grandin, Temple, and Margaret M. Scariano. *Emergence: Labeled Autistic*. New York: Warner Books, 1996.

Williams, Donna. *Nobody, Nowhere: The Extraordinary Autobiography of an Autistic*. New York: Avon Books, 1994.

Children's books about ASDs

Choose among these books for a gentle introduction to autistic spectrum disorders for siblings, young relatives, and classmates. Another good choice for helping young children understand the maddeningly literal thinking patterns common in individuals on the spectrum is the *Amelia Bedelia* book series by Peggy Parish.

Amenta, Charles A., III. *Russell Is Extra Special: A Book About Autism*. Washington, DC: Magination Press, 1992.

Gartenberg, Zachary M. *Mori's Story: A Book About a Boy with Autism*. Minneapolis: Lerner Publications, 1998. Written by a grade-school student about his brother—and very good.

Gerland, Gunilla. *Finding Out About Asperger Syndrome, High Functioning Autism and PDD*. London: Jessica Kingsley Publishers, 2000. Gerland's book is aimed at children who want to know more about their own diagnosis.

Gold, Phyllis-Terri. *Please Don't Say Hello*. New York: Human Sciences Press, 1986.

Gottlieb, Eli. *The Boy Who Went Away*. New York: St. Martin's Press, 1997.

Katz, Illana, and Dr. Edward Ritvo. *Joey and Sam: A Heartwarming Storybook About Autism, a Family, and a Brother's Love*. Los Angeles: Real Life Story Books, 1993.

Lears, Laurie. *Ian's Walk: A Story About Autism*. Morton, IL: Albert Whitman & Company, 1998.

Saguisag, Lara. *There's a Duwende in My Brother's Soup*. Manila: Lampara Books, 2001. This bilingual book in Filipino and English has super illustrations. It's a funny, sweet story about a sister's view of her brother's autism, and her attempt to understand his world.

Thompson, Mary. *Andy and His Yellow Frisbee*. Rockville, MD: Woodbine House, 1996.

Watson, Esther. *Talking to Angels*. New York: Harcourt Brace, 1996.

Werlin, Nancy. *Are You Alone on Purpose?* New York: Houghton Mifflin, 1996.

Appendix D

Case Studies

I am the mother of a wonderful and handsome seven-year-old son. My son is the absolute joy of my life. He has also been diagnosed with Pervasive Developmental Disorder, NOS.

It is difficult for me to put in to words how this diagnosis has made me feel. Joey was mildly delayed in most of his developmental milestones such as walking and speaking. I did what any caring parent does and spoke with his pediatrician about these delays. I was told that he would grow out of it and that all children develop at their own pace. When Joey was four and attending Pre-Kindergarten his teacher noticed some fine motor skill delays. I scheduled an appointment with his pediatrician and was again told that he would grow out of it. At this point I thought that if he had extra help at home with his fine motor skills that he would indeed grow out of it.

Joey began Kindergarten at five and a half (because of his date of birth). His Kindergarten teacher noticed that Joey's fine motor skills were delayed and that his work was not like "normal" Kindergarten students. I again scheduled an appointment with Joey's pediatrician. This time I was told that there were definitely some delays. The pediatrician made referrals to an audiologist, an occupational therapist and a developmental pediatrician and the screenings for special education were initiated. Joey was diagnosed as Developmentally Delayed and placed in a DD classroom.

I was not satisfied with a DD diagnoses because I wanted a specific name for what Joey had, so I scheduled an appointment for Joey at a University hospital. The psychologists there diagnosed Joey with PDD, NOS. At this point I began to feel every available emotion. I felt hopeless as I felt all of my hopes and dreams for Joey vanish. I felt guilty wondering what I had done to cause this terrible disorder. I felt anger at the pediatrician for not catching it sooner. I cried and went through a period of denial. At this point, my mother and I did a great deal of research on PDD, NOS and I realized I was not going to let this diagnosis become a self-fulfilling prophecy for Joey.

There are many theories surfacing as to what causes PDD, NOS and I am willing to try anything available to give Joey every opportunity to live a productive life. I become discouraged at times because I see the aspects of the disorder in him, especially the socialization aspects. He wants so badly to make friends and to fit in yet he does not understand exactly how to make friends. He considers it playing with another child to be in the same room with them. This aspect is heartbreaking to me because Joey is such a sweet and loving child.

This disorder is very frustrating for me and for Joey. I see so much potential in him. It's true he is different from "normal" Kindergarten and first grade students, but I know that with special help and one-on-one instruction he can succeed in school and in life. I want for Joey what every parent wants for his or her children, I want him to be happy and successful in whatever he chooses to do. It will require a great deal of work, but I now think this is possible for him. My son has many people that love him and that are willing to help him succeed no matter what. He is very intelligent and wants learn and I feel that he has the same right as every other child to learn and succeed.

The most difficult part for me has been trying to get Joey what he needs from the school system. Since this disorder is still so misunderstood, the school system is satisfied to say that he is developmentally delayed and put him in a developmentally delayed classroom where he has little chance of being challenged. My mother and I have fought very hard to have the school system give Joey what he needs. It has been a tough battle that is far from over. I intend to fight for as long as it takes to ensure that Joey receives all of the services that he is entitled to and that he deserves.

I want Joey to have the same opportunities that all children are entitled to. I want him to have friends and a career that he enjoys and that he is good at. I know that having Pervasive Developmental Disorder will be a struggle for him and for those that love him but I know the struggles and extra work will pay off in the long run because Joey has great potential and a great support system.

Grandmother of 7-year-old Todd, who has been diagnosed with PDD NOS, describes her experience:

I noticed Todd "did things when he was ready." He walked late, but it was like, he waited until he had it down pat. He never went through the toddling stage. He went from crawling to walking well. He was late with potty training, too. He did not ride a tricycle or show an interest in riding a bicycle. Todd preferred solitary activities. My daughter asked me about Todd's delays and I suggested she ask the pediatrician. Todd's pediatrician reassured her "children learn at their own pace." I had also commented to my daughter that Todd was a very "picky" eater and that he was overly interested in wrestling and videos. Todd could discuss movies like an experienced movie critic.

When Todd entered pre-K, his "disabilities" became more noticeable and problematic. Todd's teacher told us Todd could not cut with scissors and had a hard time staying focused. Again, my daughter talked to the pediatrician, who reassured her that Todd's delays were minimal and not to worry. By the time Todd got to kindergarten, he was doing very poorly in school, and watching him do homework broke my heart. He was frustrated and worried about whether or not he was "doing a good job," which of course, he wasn't.

My daughter had a meeting with the teacher and asked me if I would go. The kindergarten teacher showed us samples of Todd's work and explained that Todd could not use scissors, draw, or color. She said he had poor social skills and had a hard time staying on task. (I thought how much I disliked this woman). I asked to see the other children's papers so I would have a frame of reference for comparison. That was startling! Todd's work was terrible compared to the other children's. Todd recognized

shapes but when asked to draw one, he couldn't. His work looked like that of a three year old. I felt like I was going to cry.

Todd had a narrow range of interests and he did this "funny" thing with his hands, like he was wringing them and talking to them. Again, my daughter took Todd to the pediatrician, and this time she asked me to go. I told the doctor everything I knew about Todd's delays and the doctor asked Todd to draw a square, which he could not do. At this point, Todd was referred to a developmental pediatrician, psychologist, audiologist, and child study team. Then the roller coaster began. Todd was given test after test and we were told he qualified for special education. But no one said what he had other than developmental delays.

My daughter and I took Todd out of town to a university hospital that had a specialized child development center, to get a second opinion. Finally, Todd was diagnosed with PDD NOS. There were other diagnoses, too, like over anxious disorder of childhood, rule out depression and mental retardation. I was devastated, and so was my daughter. Then came the daunting task of going through the IEP process. Todd has done better in his "special" class, but I'm afraid he will be stuck in that track. He is in a resource room for most of the time with not much inclusion in general education class. I have had to advocate for Todd at school to make sure he gets what he needs. I support my daughter, because I know she is hurt and confused by all this, but it has been difficult for me, too. I have felt such despair and worry about Todd's future and about my daughter.

Going through this process of getting a diagnosis, finding treatment, and working with the school has been tiring. It has taken two years, and not a day has passed that I have

not felt sad for my beautiful, loving grandson and my daughter. I have educated myself on PDD NOS so I will know what to look for, be able to give Todd what he needs, and support my daughter. I have talked to professionals and my grief gets better, and then, when Todd hits another developmental milestone and flounders, I feel grief again. I would encourage parents and/or grandparents who are going through this to seek out a support group, and possibly, a professional counselor. I would also encourage them to talk about their feelings, difficulties, and successes to others.

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